AT: Welcome to the Infinite Women Podcast. I'm your host, Allison Tyra, and today I'm joined by Dr. Jill Inderstrodt, a research scientist at Regenstrief Institute to talk about the intersections of technology and maternal health. So first, could you introduce us to the research that you're personally doing?

JI: I am in maternal child health informatics, and so I have a couple of different tracks to my research. One is in public health surveillance of congenital conditions. And so I'm based in the United States, and I have grants and contracts through the CDC and also through the National Institutes of Health to do public health surveillance, which is basically taking different data sources that have to do with maternal health or child health, linking those data sets together. So for example, taking electronic health record or EHR data sets, public health data sets such as birth records, death records, fetal death records, and then also sometimes it can also include Medicaid billing data or other data sets, taking those together and then trying to produce information about how many people have conditions, what types of people have different conditions, and what are the long-term outcomes for individuals who have those conditions. So for example, one of my major grants is surveillance of congenital heart defects, and so we're trying to figure out how many people in my state of Indiana have congenital heart defects, and then also what's their long-term health look like. So I also surveil with with my teams stillbirth, neonatal abstinence syndrome, congenital syphilis, among other conditions. It can also be interesting too because the maternal health record and the child health record are not necessarily linked in systems, and so we have to do some technological or sometimes even algorithmic jumping jacks or cartwheels to try to get those two together, to try to match those with each other. And then my other work is on the prediction of maternal health conditions, particularly maternal morbidities like preeclampsia, and trying to use AI and machine learning to develop technologies that will help to treat those conditions, especially for moms who live in areas of obstetric deserts. And so in Indiana, we call them Hoosiers, about 40% of Hoosiers live in an area where they can't immediately access obstetric care or a labor and delivery unit in a hospital. And so this is a really great opportunity I think for AI to maybe be utilized to serve those communities.

Listen to Kaley Butten on Frances Oldham Kelsey or read the transcript.

Listen to Alexis Pedrick on medical racism or read the transcript.

AT: It's interesting that you bring up rurality specifically, because on a previous episode I chatted with someone here about an app in Australia that helps both a patient and their doctor monitor gestational diabetes. And I also live in a regional area where we really do not have sufficient medical personnel to meet the demands of the community. And so when I heard about that app, I immediately said, "oh yeah, that's one application, is rural and regional women in particular who, as you mentioned, may have difficulty accessing medical services." But we do know that technology can be a double-edged sword because it does bring with it the biases of its creators, and certainly as a data scientist, you would know that the data sets that are used to tell these programs what's good, what's bad, are often also biased. And so when we get into things like racism and sexism in triaging systems and diagnostic tools. So what are the ways that you see technology either narrowing or broadening the gaps in how patients with different marginalizations are treated?

JI:Technology, and in particular predictive technology like AI, has enormous capacity to do both. So to really help to serve women or mothers who might be in areas that are underserved, but also to maybe increase those disparities between groups who have that immediate access and groups who don't. I know one of the things that we're looking at with one of our projects, so we've developed a machine-learning algorithm that will predict preeclampsia using minimal EHR data, electronic health record data. And so our goal with that was to be able to apply it to anybody regardless of at what point they entered prenatal care. So we know that for different groups, they enter prenatal care at different times. Women who have fewer resources are more likely to wait to access prenatal care for many different reasons. It can be because they just have to work and they can't get an appointment. We hear from a lot of women that they just can't get an appointment in enough time. It could be because of childcare issues. It could be because they don't know they're pregnant, lots of different reasons.

We try not to put that responsibility necessarily on the mom and recognize the larger structural problems there. But one of the things that we're doing with that is trying to integrate it into technology that will allow them, just like you said with gestational diabetes, to then communicate with a physician in a larger metropolitan area or their nearest town that has an obstetrician. So that if it looks like they're becoming pre-eclamptic, or even if just their blood pressure readings are of concern, that they can be provided with the proper guidance to then get to a medical center if needed.
And one of the things that we're doing with that is, we are actually engaging community members, not necessarily in the development technologically, but in the development in terms of feasibility, usability. But even just trying to get at, what do individuals in the communities that we plan to serve think, what do they know about, how do they feel about artificial intelligence for healthcare use? Because if you have a population or a subset of a population who is very doubtful or who is very distrustful for really valid reasons of AI or of technology in healthcare, it doesn't make sense to be developing technologies for them if they're not going to be used or if they're not going to be well received. And as we get further funding for this, we're seeing that the calls for funding are also requiring that community-engaged piece. And we call that community-engaged research. We use methods like participatory rural appraisal, focus groups, interviews to really get at how we can design products that are with the actual population in mind. And so I think that that is definitely the first step. And that is hopefully a way that leads to eliminating geographical disparities while there is definitely the potential that if there are very helpful technologies and only folks who have the technological know-how or the capabilities or the literacy to use them, use them, that's not going to improve health conditions. It's not going to improve the data. We're not going to see fewer people sick and we're not going to see fewer people die. And so that community-engaged piece I think is really, really important. And it's also something that's becoming more expected. And so that is very encouraging on our side as researchers, that we're not being given a carte blanche “go design to solve this problem.” We're also being asked to find out how communities view the problem themselves and how they view the solution and what part of that solution they want to play.

AT: In addition to the distance and the time concerns, so for example, if you have to drive an hour to go see a doctor and appointments are only available during a nine to five workday, you might end up having to take at least half a day off work just for a doctor's appointment. Apart from obviously that is a very practical concern, particularly if even if we're not talking about work, if you have other kids in your care, anyone needing to take say three hours for a single appointment is not practicable for many folks. But in the US in particular, do you think that this will also help make healthcare more accessible from a financial standpoint?

JI: I'm not a health economist and so I don't purport to know much about how it affects affordability for individuals. I will say that based on some analysis that I've done with colleagues on other programs, giving people more healthcare access doesn't necessarily show financial gains in the immediate future. So for example, I'm thinking of a project that we evaluated that was for a congenital condition and we were able to show that infant mortality decreased with more access to programs. However, spending increased and we don't know exactly the reasons because it was purely using Medicaid data and so it wasn't even using electronic health record data, it was using the billing data. So we weren't interviewing people. We were really just trying to surmise based on what we see. But what we did see was that, for example, babies were not missing their well-child visits. They were hitting all of those well-child visits. Well, that's going to be more expensive. We actually saw more emergency room use and we think that one of those reasons might be that because they were in a program and they were connected to a nurse, the nurse would tell them, go ahead and go to the ER because something was urgent. And as a result, we see less infant mortality. And so I can't necessarily speak to, at the individual level or at the state or federal level, but more healthcare access is always good. A lot of times when we're talking about people who are under-resourced or who are in rural areas who might not have high incomes, we're also talking about individuals who are, in the United States Medicaid, which is essentially the government pays for your health care, which I know in a lot of countries is

just standard. But because of that, the cost for parents or the cost for families doesn't tend to be in the sort of day-to-day. Medical costs are like what you're talking about, missing work. It could be in increased co-pays depending on what kind of insurance they have. So I think anything that does remove an extra trip somewhere, like you said, is hopefully going to save a family money, which in the long run is good.

AT: And there's also the aspect of preventative care reducing long-term issues. So it might be, well, if that nurse hadn't told that person to go to the hospital and get that checked right away, something worse would have happened, which in addition to the health consequences and the practical consequences for that person and potentially their family, that also could have been. But then she didn't have to miss a week of work, for example, because those worst consequences didn't happen. So I don't want to make this all about finances. Obviously, good health is a goal in and of itself. But I know that particularly in the US, that is one of the really concerning things about seeking medical care. I was actually in a position a couple years ago where I had to go to the hospital here in Australia and I'm literally lying in the ER. It's during COVID and my biggest concern as they're talking about surgery and they're doing all these tests was, I asked my husband, "how much is all this costing?" I don't want to lose our home, for example, because I got sick. And he had to actually explain to me, "you're in the ER. This is covered. You don't get charged for this." And he had to kind of talk me down because I grew up in the US because that was my default assumption is an ER visit can mean that you lose your home. So that's why I wanted to bring it up. Not that everything is about money, but a lot of things are.

JI: It is definitely unique, I think, to the United States, the medical debt issue.

AT: Now, I want to come back to this question of health surveillance, because you did tell us about the sources that you are getting your data from, but particularly since the overturning of *Roe v. Wade*, for example, people who menstruate have been warned to delete period tracking apps because that data could later be used against them if they're accused of obtaining an abortion illegally. So when it comes to technology and surveillance, particularly around maternity, I think there are a lot of very reasonable and valid concerns that people who might use these tools might have because of how that surveillance might be used against them.

JI: Yeah, and I just want to reiterate too that when I talk about public health surveillance, I'm talking specifically about systems that use electronic health record data, public health data sets that come from, in our case, from the state Department of Health, sometimes Medicaid billing data, data that comes from hospitals most often. And so there are obviously always going to be exceptions where there's different projects and programs that are being run out of different hospitals. Overwhelmingly, when you use a period tracking app, it doesn't automatically get plugged into your electronic health record. However, if you have a positive pregnancy test, an obstetrician or a primary care physician or the ER, that would show up in your electronic health record. And so I do think that it is reasonable for people who get periods to be concerned that that data could be used in a negative way. And I'm not a legal expert. Again, I really just deal with the data, with the back end of electronic health records. But I do know that there have been instances, for example, in the United States, there was an instance where a medical center had medical records subpoenaed under the premise that there was some Medicaid fraud perhaps going on, or that specifically the medical center was paying for procedures related to transgender kids that had been outlawed at the state level. And so they wanted to see whether or not they were being billed for these services. And so that's how they were able to gain access to the records.
And I would say that the medical community responded quite forcefully in arguing that that went against good medical practice. And again, I'm not a lawyer, so I don't know the legal implications of this. But the medical center felt like, "yes, but the legislature said that we had to, the attorney general said that we had to, and we have to comply." And so I think that right now, there is this tension between what is private in general. And I know that a lot of people are very concerned about that. I think that there are alternative applications now, and there have increasingly become more and more alternative applications for people to track menstruation,

where it lives on your phone and not in the cloud. And it's not owned by a third party. And so from what I've read, it's very important to read your disclaimers, read the terms and conditions to see who has access to that data. So far, we are seeing, across the country, individual instances of individual data. And this isn't necessarily menstruation data or abortion data or anything along those lines, pregnancy data. But we are seeing people's data being subpoenaed in cases involving reproductive health. And so as a non-legal expert, that's all that I can say on that. I do know that medical centers in general, they do have an incentive to continue to keep your information private. But you also have to think about the bigger picture, which is that data breaches occur all the time in all kinds of venues. And so if you shop at Target in the United States, and you have an account with them where you type in your phone number every time you go to the cashier, and you get discounts or whatever, and then maybe you get a notification that says, "hey, it might be time to buy probiotics." If you are doing something like that, that is health data in a way. It's not health data that I can access, but there can be data breaches. And there have been huge data breaches. There have been data breaches by credit card companies. So if you paid for a copay at an abortion clinic.

AT: Yeah, I've heard stories about you buy, say, a pregnancy test at Target, and then suddenly you're getting ads for baby stuff, and it just creeps people the hell out.

JI: Or even coupons sent to your house. I've heard stories, and again, this is not academic, but I've heard stories of people where Target knows they're pregnant before they do, because it's been so many weeks since they bought tampons or something. So health systems data gets breached as well. And so yes, I think that the fear of period tracking data is real. I think that the bigger picture is that we do give a lot of data that we can never be 100% sure is secure.

AT: So the kind of work you do, I would imagine, is in theory, very useful for decision makers. So people like legislators who are hopefully, not always, but hopefully, using information like what you're able to provide with your research to shape what is best for people. Do you see that happening? And what would you like to see in terms of how your research is able to influence decision makers who can use that information to make people's lives better?

JI: So I think that right now, one of the big places where legislators and research and I think community-based organizations can come together in a state like Indiana, which is very restrictive in its reproductive health policies, is around issues of infant mortality. And a lot of the work that I do, and that the teams that I work on do, is aimed at looking at, why do babies die? And also stillbirth, which I would not include in infant mortality, but as a continuum of infant mortality, because it can have some of the same causes, although it doesn't always. That both lawmakers and research and the medical community and community-based organizations are all committed to lowering the rate of infant mortality in the state of Indiana. And so a lot of the work that I'm doing right now and that my teams are doing right now is aimed at illuminating, what are some of the reasons that babies die? Or what are some of the reasons that babies die prematurely when they're very much wanted by families and expected to survive outside of the womb. And so one of the things that we try to do is even if we're doing maternal health research, for example, if I'm researching preeclampsia, is to make sure that I'm tying that to infant outcomes. And so that can be done in an informatic sense. That can be done by linking moms and babies together, as I discussed, how we can, on the back end of electronic health record data, match moms with babies so that we're not just looking at mom's health, but we're also looking at baby's health well into childhood.
I think that when we can talk more about the things that cause these problems that are difficult to research, and stillbirth, for example, is notoriously difficult to research. And not to get too wonky, but a lot of the work that I do is concentrated on trying to find the sources of stillbirth data that can allow us to learn more about the stories behind stillbirths. And so with stillbirths, a large majority of those, we have no answer as to why they occurred.

One of the reasons that it's hard to study stillbirth is because we don't have many fetal autopsies. And in the United States, one of the reasons that we don't have a lot of fetal autopsies is because Medicaid does not reimburse for fetal autopsies. Also because moms and families, very understandably, are hesitant to find something that could suggest that they should have done something differently. As somebody who has been pregnant, I think constantly about how the things I did during my pregnancy affect my child today. And part of that is being a maternal child health researcher, that I'm probably a little hypersensitive to that. But I can imagine what it would be like to be afraid to know that something that occurred during pregnancy that was under your control could have possibly caused fetal demise, caused stillbirth. And so that's another reason that we don't have the autopsies that we need is families don't want them. But then studies show that they regret that later. And so at the provider level of nurses and doctors, there's also a skill development component, which is do nurses and doctors know how to talk to families when they're in some of their darkest hours about this medical decision that they have to make.
We also find that fetal death records are not always reliable. To speak to a legislative success that was completely unrelated to anything that I did, but our fetal infant mortality specialist here in Indiana, her name's Linzi Horsley, something that she just got passed was that the fetal death record originates at the hospital, whereas in Indiana, it used to originate at the funeral home. And so the data wasn't as reliable because there wasn't a medical professional who had been involved with the family who was filling out this fetal death record. So a lot of times the data wasn't correct. A lot of times in hospitals, in the electronic health record data, stillbirths are miscoded or misclassified as a miscarriage, or they might be mis-categorized as a live birth. And so what we're doing on our end is working to try to get all of these pieces to fit together so that we can tell better stories about fetal loss and about infant deaths as well. And so I would say that almost all of my work, congenital conditions, maternal health, pretty much everything that I do is aimed at improving maternal health and improving reproductive health, but always with that context of infant mortality, of making sure that all babies can survive outside of the womb, live a regular long life. And I think that the research that we produce has the potential to influence policies like Medicaid paying for stillbirths, for example. That's not necessarily something that's on my agenda, but I think that those things do come about when we do research that finds that we have reasons why we might know or not know why babies die.
We have partnered with the city of Indianapolis, with the mayor of Indianapolis, and the city of Indianapolis has raised funds external to any tax dollar-affected money to give guaranteed basic income to moms who live in the zip codes with the highest rates of infant mortality in the city. We also have our county and city are the same thing in Indianapolis. So it's a fairly large area. And so moms will get $300 from the point of entrance into the project until their baby is three years old. So one of the main targets there is this issue of infant mortality. We want to see if giving moms financial support leads to better infant health outcomes while also studying maternal health outcomes at the same time, which is always very important for us. That is an effort of government, of research on the evaluation side, but then also a lot of community organizations coming together to make sure that we're reaching, recruiting the right families to participate. And I won't get into the technicalities of how we are selecting moms for the program, but that is all aimed at improving health outcomes, but in particular, improving mortality. One of the things about infant mortality is it is very challenging to show improvement because we're talking about very small numbers. So in Indiana, around 500 babies die every year before their first birthday. And so if you think about that spread out throughout the state, that's not many per zip code. And so we can though show an improvement in the conditions, mom's conditions and baby's health conditions over time that we know do lead to increased infant mortality.

AT: I will say that I think that there is a bias among a lot of people that, like you were saying, hopefully we can all agree that infant mortality is not acceptable and hopefully we can agree that everyone should be working together to reduce that. But I want to shift focus to maternal mortality, so not the infant, but the mother. And the U.S. notoriously has significantly higher maternal mortality rates than any other high-income country. And in fact, it's not only increased, but doubled in recent decades. So for every 100,000 live births in 1985, there were

only 10.7 deaths, whereas in 2020, that number was 21.1. So I have to assume that that doesn't factor in deaths that may be related to other factors like postpartum depression, for example. I'm not the data scientist, maybe I'm wrong on that front. But what are the ways that you think that technology can help reduce the preventable deaths?

JI: Yeah, so when we talk about maternal mortality, it's important to differentiate between pregnancy-associated and pregnancy-related. Pregnancy-related deaths are those that are either due to a chain of events that are initiated by pregnancy or the aggravation of an unrelated condition by the physiological effects of pregnancy. So in Indiana, the top causes of pregnancy-related deaths, for example, are cardiovascular, so preeclampsia, hypertensive disorders of pregnancy, eclampsia, HELLP syndrome. But others include, the top ones include overdose, homicide, automobile crashes. And I don't know how the data has trended over time from the years that you gave, but I think we need to pay attention to the fact that homicide, overdose, mental health conditions factor very heavily in the year following delivery. So that can be from myriad conditions. Homicide can be from living in a bad area, or it can be from living with a bad person. We don't know every single one of those stories. I think technology would play different roles in different conditions. There are a lot of informatics interventions for maternal mental health. In fact, I recently conducted a review, a scoping review to look at what kinds of informatics interventions existed for maternal morbidity, and that includes severe maternal morbidities. So things like hemorrhage and overwhelmingly, those interventions were for new mental health conditions following pregnancy. Other top conditions include gestational diabetes and then to a lesser extent, preeclampsia, very few actually for hemorrhage, even though hemorrhage is a key cause of pregnancy-related death. And so there are things that are being done with apps, with programs, with online group support that are aimed at addressing these conditions that don't necessarily lead to death, but that cause death within that one year following pregnancy.
From our end, so on our side of things, as I said, we're looking to integrate our machine-learning models into technology that will help moms who might be at risk for preeclampsia, so high blood pressure in pregnancy. That can be both preventative in the sense that during pregnancy, they'll be taking their blood pressure readings and then looking to see if there are trends that might cause them to need treatment. And obviously, if they get treatment, that can lead to fewer deaths. But there are also a lot of good programs that are looking at that postpartum period. And so in the absence of postpartum doulas, lactation support, going to that six-week appointment, which we know is really, really important, but we know that many, many, many women miss for many, many different reasons. There are apps and programs that are being developed to address in particular that one year following delivery. And so, yes, I think that technology and in particular, things like applications and remote monitoring, and even AI for things like chatbots, where moms can get answers to concerns or questions that they might have, in the absence of any other care, hopefully will serve as an alternative.

AT: Join us next time on the Infinite Women podcast. And remember, well-behaved women rarely make history.