MAYA SABATELLO: Good morning, afternoon, or evening, everyone, depending on which part of the world you are Zooming into today. I'm Maya Sabatello, and I'm delighted to welcome you to our June ELSI Friday Forum, titled The Impact of the Supreme Court's Dobbs Decision on Prenatal Genomics Research and Practice.

The Forum is hosted by the Center for ELSI Resources and Analysis and is usually held on the second Friday of every month for one hour starting at noon Eastern Time. We also have a Zoom room reserved for more informal discussion immediately after the panel for 30 minutes.

For those of you who might be new to the Center for ELSI Resources and Analysis, or CERA, we provide resources to support research on the ethical, legal, and social implications of genetics and genomics, and serves to connect scholars, scientists, policy‑makers, journalists, members of the public, and others to engage in ELSI issues. CERA is funded by the National Human Genome Research Institute, or NHGRI, at NIH, and is managed by teams at Stanford and Columbia Universities in partnership with the Hastings Center as well as Harvard University. I encourage you to visit CERA's online platform, ELSIhub.org, for the recording and transcript of this forum and related references.

We are also excited to announce the publication of three new ELSIhub Collections: Ethical challenges in obtaining informed consent for genetic/genomic research, curated by Lisa Parker; addressing algorithmic unfairness in health care by Charlotte Tschider; and abortion and the genetic counselor: the impact of restrictive legislation on genetic counseling practice, by Laura Hercher and Jordan Brown.

Please also go to the website to join the ELSI Scholar Directory, sign up for newsletters and other events like this one at ELSIhub.org, and get daily updates and news on Twitter.

Some quick housekeeping information before we move on to the panel itself. So if you wish to use closed captioning, please turn on the CC button at the bottom of your screen. The panelists' presentations will be very brief, in order to conserve a significant portion of our time for discussion. Please use your Q&A button, which you will find at the bottom of your screen, to write in questions for the panelists at any point during the session. We will collect those questions later on and have ‑‑ and bring them to the presenters' attention.

You can register your enthusiasm for a question and elevate it up ‑‑ up the list by using the upvote button in the Q&A box.

The chat box is available for further engagement. We will posting links to resources referenced in today's discussion there as well.

So if you have any questions, please e‑mail info@ELSIhub.org at any time.

I'm now delighted to introduce the panel's moderator, Dean Kimberly Mutcherson. Dean Mutcherson, who is a Co‑Dean and Professor of Law at Rutgers Law School in cam den. She is a reproductive justice scholar whose work focuses on assisted reproduction and abortion among other topics. Um. Cambridge University Press released her edited volume, Feminist Judgments: Reproductive Justice Written in 2020. In 2021, Dean Mutcherson received the Association of American Law Schools inaugural Impact Award as a cofounder of the Law Deans Antiracist Clearinghouse Project. And she received also the Center for Reproductive Rights Innovation in Scholarship Award in 2013, a Chancellor's Teaching Excellence Award in 2011, and the Women's Law Caucus Faculty Appreciation Award in 2011 as well as 2014. Dean Mutcherson has been a senior fellow or sabbatical visitor at the Center for Gender and Sexuality Law at Columbia Law School and a visiting scholar at the Center for Bio‑ethics at the University of Pennsylvania. She received her BA from the University of Pennsylvania and her JD from Columbia Law School.

KIMBERLY MUTCHERSON: Thank you so much, Maya. It is really great to be here with you today, although the topic isn't one that all of us are, ah, eager to talk about. Although we certainly have to talk about it.

So my first task this morning, afternoon, evening, again depending on where you are, is to set the stage a bit by talking about what is going on in Dobbs versus Jackson Women's Health and why it's relevant in this particular context. So I want to go back to 1973, which is when the Supreme Court decided Roe v. Wade. And usually when people talk about Roe, they just say, oh, the Supreme Court found there's a constitutional right to terminate a pregnancy. Which is true. But they also created a very specific framework for that right. First of all, they said it is a fundamental right, which means it is one of the most important rights that is derived from the Constitution. They said that states have an interest in prenatal and ‑‑ sorry, I won't say prenatal. They have an interest in potential! Life. That they are allowed to assert at various points during a pregnancy. And then they said that the way that states can regulate abortion is very specific. And they focused on trimesters. So they wrote that in the first trimester, states cannot regulate abortion at all; in the second trimester, states can regulate, but they can only do some in, um, the interest of the health of the pregnant woman; and then in the third trimester, they could regulate and go so far as to ban abortion, but they would always have to have an exception for the life and the health of the pregnant woman.

So, Roe really laid down a fairly strict construction of how to think about regulation of abortion in the United States. In 1992, the Court decided a case called Planned Parenthood versus Casey, which was the first sort of significant reversal of what the Court said in Roe. They did not call it a reversal, but those of us who do this work recognize what happened in Casey. So, the statute that was being challenged was from Pennsylvania, and it had a bunch of different requirements in it, including a spousal consent requirement, lots of reporting requirements, 24‑hour waiting period, sort of all the good stuff that, ah, states have tried to put on the table for many, many years. So in Planned Parenthood versus Casey in 1992, the Court said we still believe that the Constitution protects a right to terminate a pregnancy ‑‑ that it is part of our right to privacy, and it is found by pulling together multiple amendments of the Constitution. But! In our previous decisions ‑‑ this is the Court. In our previous decisions, we did not give enough weight to the state's interest in potential life, and so we're gonna take this opportunity, now, to fix that. And the way that they fixed that is they said we're gonna throw away the whole trimester framework that we came up with, and now we're just gonna switch to liability. So the line between how you regulate is the line of viability ‑‑ which, of course, is in the 20th weeks of pregnancy; 24, 25, maybe a little bit earlier. (coughs)

So. The Court said that basically, states can do a LOT of things to regulate access to abortion: that waiting periods are fine; that you can require consent or notification for the parents of a juvenile, as long as you have a judicial by‑cross ‑‑ bypass procedure. You can have, um ‑‑ you can force people to wait 24 hours. You know, all these other sorts of things. The only piece of the statute in Pennsylvania that the Court struck down was the spousal consent. They said that was a ‑‑ that was going too far. But other than that, um, the other ways that Pennsylvania had chosen to regulate were perfectly fine.

And again, the bottom line was there is a constitutional right to abortion; states can regulate abortion; that women do not have the right to be totally insulated in making the decision to terminate an abortion; and that viability is now gonna be the line that marks what kind of regulation can happen. Post‑viability, states can regulate and go so far as to ban abortion, but again: still have to have the exception for life and health.

So, both cases really reinforce the state interest in potential life. And the Court has been elevating that interest, and thus the state's ability to regulate pregnancy and abortion, ever since Casey.

In Dobbs, the issue is a 15‑week ban in the state of Mississippi, which of course is well before viability and is a clear violation of the rules set forth in Casey. So, the fact that the Court took this case at all was the first sign that things were gonna go south. So, what we've seen in a leaked opinion from Dobbs is that the plan for the Court is to overrule Roe and to overrule Casey, which will send this issue back to the states, where each individual state will get to decide what the future legislation is in their jurisdiction. What this means is we'll see abortion banned in at least half of the states in the next several months. So probably by the fall, half the states will have decided abortion is completely illegal in their jurisdictions. But there will still be lots of questions left to ask, and that's where you in this community come in.

So some of the questions that will still be on the table: Does the state interest in potential life extend to embryos? And if so, what does that mean for the fertility practice and fertility industry? Can states regulate what kind of genetic testing is okay for embryos or a fetus and then make proclamations about how people can act on that information? So for instance, could a state create what are called, in abortion cases, a "reason ban" that forbids certain types of behaviors based on why you're doing them? For instance, states have attempted to ban abortion based on a disability diagnosis or because of race. Can the state regulate the informed consent process for genetic testing, as they've done for abortion in several states, and dictate what has to be told to patients? And then ‑‑ so we're going to spend some time today talking about both what's already happening in places where abortion is severely restricted and what we can expect to happen in the months and the years to come.

So my job now is to introduce our panelists for today. And you'll gonna go ahead and start with, ah, Aarti Ramdaney, who is a prenatal genetic counselor with the University of Texas ‑‑ with UTHealth in Houston, um, and who is an Assistant Professor with University of Texas McGovern Medical School. She helps families understand their individualized risk assessments and the benefits, risks, and limitations of reproductive genetic testing. And she also has a special interest in psychosocial issues and access to reproductive options, and she has authored several publications in various areas of clinical care. And she is also a clinical supervisor for various trainees.

The second person I'm gonna introduce is Alison Norris, who is stepping in as a pinch hitter! And I think I'm confident about what that means, in this context? Um! And she is a associate professor in Ohio State's Colleges of Public Health and Medicine, where she focuses on sensitive or stigmatized subjects. Dr. Norris employs multidisciplinary methods to investigate access to contraception and abortion, prevention of unwanted pregnancy and sexually transmitted diseases, and knowledge and stigma about sexual and reproductive health topics. She is the co‑Principal Investigator of the Ohio Policy Evaluation Network, or OPEN, an interdisciplinary research program that studies the impacts of reproductive health‑related policies and laws on the health and wellbeing of Ohioans.

And Michelle McGowan will be jumping in at some point. Michelle is an associate professor in the UC Department of Pediatrics and Department of Women's, Gender, and Sexuality Studies. She assesses the impact of the abundance of technologies available throughout the reproductive health care system, studies the inequitable distribution and access to these technologies, and is also interested in learning about different disparities between communities and populations and systemic problems in precision medicine.

So those are the folks that we're gonna hear from today. I'm gonna turn it over to them, and then be prepared to start peppering them with questions once they're done with their presentations. So, I will stop talking, and I'll give it to Dr. Norris.

ALISON NORRIS: Thank you so much, Dean Mutcherson. Thank you also for the excellent introduction about the legal, um, situation that brings us to where we are today. I'm gonna talk with you about a research project that Michelle McGowan led with our group from the Ohio Policy Evaluation Network. (clears throat) This is a body of work, um, working with clinicians who are what we call abortion‑adjacent. They're folks who are not abortion providers, but are working in the health care space. And this particular analysis will be, um, focused on work we did with genetic counselors. Because we think that the experiences of the genetic counselors in Ohio ‑‑ which is an abortion‑restrictive state currently ‑‑ will be useful to inform, um, how genetics may be practiced in the post‑Dobbs era... that is on the near horizon. Next slide, please.

This is a busy slide of the United States, and it illuminates what Dean Mutcherson was saying about ‑‑ (clears throat) What will likely happen in the coming weeks, and months, as... after the Dobbs decision. So, post‑Dobbs, or post‑Roe. And the darker brown shows the states that will be having trigger bans, or have other kinds of bans that mean that as soon as the decision comes down, the laws in that state begin to change. (clears throat)

And we give this context, because Ohio is already experiencing many of these restrictions, and you will hear the quotes from participants in the study who talk about how those restrictions impact their practice. And what you're looking at here, with the map of the United States, is the ways in which these experiences of counselors in Ohio are likely to be playing out across the country in the coming months.

And I'm delighted that my colleague, Michelle McGowan, has joined us, and I'm going to turn the mic over to her for the next slide, please!

MICHELLE McGOWAN: Thank you so much, Alison. And thank you all for being here today. Sorry I'm joining us a little bit late.

So, as Dean Mutcherson and my colleague, Alison, mentioned to you, we have been doing research with abortion‑adjacent providers in states that are already restricting abortion in ways that were permitted by the Casey decision in 1992. And we thought it might be helpful today to think about this question, about how reproductive genetic counselors' experiences with abortion regulations NOW can give us some insight into how the Dobbs decision may impact genetic professionals and their patients variably across the country.

And so, this article that's been posted in the chat was published in Journal of Genetic Counseling in December where we asked groups of genetic counselors across the state of Ohio how the various myriad regulations of abortions that had popped up in the state in the last decade were impacting the care that they provide with prenatal patients. Next slide, please.

So, the ways in which I'm going to approach the findings here are not to read the quotes to you, but rather to give you the opportunity to read them on your own or to read them in this paper, and to answer this question: How did the experiences of genetic counselors who are already working in abortion‑restrictive environments ‑‑ experience abortion regulations? And the first thing we heard universally from participants was changing abortion regulations creates a lot of confusion for abortion and genetic counselors for what care they can give to their patients. Regarding referrals; regarding what kinds of procedures should be available to them should they decide to terminate a pregnancy due to a fetal diagnosis. And it creates so much confusion that some genetic counselors created referral sheets where they tried to understand what clinics were offering at any given time that they shared amongst themselves, and other genetic counselors that we talked to said every time they had a patient that would present with the possibility of ending their pregnancy, they would be calling the local abortion clinic to try to figure out how to advise them about what was available in their region. Next slide, please.

All of this, um, then, is important for us to understand, because we heard over and over again that genetic professionals ‑‑ and in this case, genetic counselors ‑‑ express that they felt that the, their patient advocate role was really strained by externally‑imposed regulations. And so what you can see from this quote here is that though the counselors we talked to were really interested in trying to lay out all of the options that were available to patients, as soon as they started to explain to patients what the regulations were that may impact the availability of abortion in their state or in their region, they got the impression that patients were angry, that patients felt stigmatized, and that they felt judged for even considering a decision to terminate what, in many cases, was a wanted pregnancy. Next slide, please.

And so, we heard often that, you know, one of the core tenets of genetic counseling is nondirectiveness. And while nondirectiveness as we know has undergone a lot of debate within the field of genetic counseling, oftentimes genetic counselors in the prenatal sector said, look, we're really trying to support patients' autonomy, but in states like the state of Ohio where we have a limit such as 21 weeks since the last menstrual period, and many don't come in to talk until mid pregnancy, they're really, really constrained. So we've heard this over and over again: The option that are presented to people aren't truly free and informed choices that can be made in a, you know, taking as much time as you like. But in fact, there are external pressures put on to them and to the counselors as to telling them what choices are available to them. In this case, 24‑hour waiting periods and gestation rules can have a huge impact. Next slide, please.

Further, we also learned that because in part of the dynamic nature of state regulations related to abortion that seem to be churning ALL of the time in OUR state, we found that some institutions interpreted state regulations in anticipation of them going into effect, and sometimes changed or reversed course on prior policies that had been more permissive around providing abortion care in hospital settings once they knew what the diagnoses were for which those terminations for taking place. So for instance, the state of Ohio currently has a Down's syndrome diagnosis ban, meaning that no one can give Down's syndrome diagnosis as the reason for seeking a termination. And the legal penalty is to the health care provider, the physician who would provide an abortion knowing that that was the reason. But in our state, there were some institutions that changed their policies around terminating for Down's syndrome diagnoses even before the law went into effect, because it was wrapped in the courts for so long. Next slide.

So as I mentioned, putting gestational limits on abortion care can be very restrictive for patients who may receive a diagnosis at the midpoint of pregnancy, as you can see in this case: a genetic counselor who would be practicing in the state for quite a long time said there was a really big difference between when the state went up to 24 weeks of viability and had viability testing, versus when they went to the 22 weeks since last menstrual period, in terms of the amount of time that patients had. Next slide.

And what we've found ‑‑ which is reflective of the broader literature on reproductive health care access ‑‑ is that regulatory diversity, and various regulations of abortions, have the potential to ‑‑ and we all know, DO ‑‑ exacerbate health disparities, which can constrain reproductive autonomy. The examples I give here are of how people who have public insurance are disproportionately affected by abortion bans on that coverage from federal and state sources, and that people who have unreliable transportation or complicated logistics to manage in their lives ‑‑ including managing a job and child care and not having reliable support systems to step in and provide that care, if they want to seek abortion out of state or at a long distance ‑‑ they may be... um, it may be impossible for them to seek an abortion even if that's what they desire. Next steps.

And so what we've projected in a paper that we published just last month, in Perspectives on Sexual and Reproductive Health, is that... the Dobbs decision could result in dramatically increasing the travel distance by car that patients in the state of Ohio would have to take in order to secure an abortion. Currently, the farthest anyone would need to go is 99 miles by car. But depending on what the regulations are in states surrounding Ohio, those ‑‑ some ‑‑ in photo B here, we see Pennsylvania and Michigan and Illinois may be more permissive, at least in the short term. So that may increase the driving distances by some length of time. But if all of the surrounding states of Ohio become more restrictive, people will be traveling as far as Illinois, Maryland, and Virginia to seek abortion care from our state. This is a dramatic increase in distance, and will become insurmountable for many who seek care. Next slide.

So, the findings of our studies suggest that abortion clinics may be the target of a lot of abortion regulations, but these regulations do impact abortion‑adjacent health care professionals, including genetic counselors. And we heard over and over again that access to reliable and consistent sources of information about which dynamic regulations ‑‑ ah, which abortion regulations ARE in effect in a dynamic regulatory context were really needed by this population ‑‑ that doesn't pay attention to it necessarily on a day‑to‑day basis! They need to know what abortion services are available statewide and within their region. And it would be good for them to have better access to resources as far as what is available with funding for patients who may not be able to afford abortion coverage or pay out of pocket.

And we argue that there are opportunities for professional societies who haven't historically been at the center of the abortion debate and the abortion lobbying to develop educational resources for their constituents and to engage in legislative advocacy to address the burdens of abortion regulations on the professionals of their profession and the patients they serve.

And I would like to thank my funder and all of my collaborators on this work. And I'll turn it over now to Aarti! Thanks!

AARTI RAMDANEY: Thank you so much, Michelle and Alison. And I'm honored to be part of this discussion today. As a practicing prenatal genetic counselor in Texas, there have been many, many things since the restriction went into effect almost a year ago. For my portion of today's discussion, I wanted to reflect on the implications of the anticipated Dobbs decision and how we may need to re‑examine prenatal genetic care, and the importance of increasing education for students in genetics. Next slide, please.

I do not have any financial conflicts of interest to disclose. The opinions and discussion I present are also my own, and not the views of my employer. Next slide, please.

I want to start by presenting the chart ‑‑ typical timeline of genetic testing in which most individuals who know that they are pregnant by the first trimester and have access to health care may start to have a discussion on testing options at around 10 weeks gestation. I will note that around one‑third of our patients in our Texas clinics do not actually present for care until the second or third trimester. So a lot of our patients, they might not be available until at least 13 or 14 weeks gestation. I think Dobbs calls on us to examine this timeline and how it may function under new legislation. Given my experience and patient population, I do find most patients who would not consider abortion as an option for their family still do elect some level of testing ‑‑ typically noninvasive ‑‑ for preparation or reassurance purposes. However, we do see many families reassess their decisions once faced with a high‑risk result or abnormal ultrasound finding, particularly if severe. And the question becomes how do we provide the most accurate information to these families to make an informed decision without potentially INcreasing the challenges to accessing abortion services.

So I don't think I have to preach this to the current audience today. There... is very little that is definitive in the world of genetics, or in ultrasound. And oftentimes there is some level of uncertainty, or a spectrum of a prognosis. And so, if we DO see a finding that is associated with an underlying genetic syndrome ‑‑ whether it be a heart defect or abnormal testing results ‑‑ how do we discuss the benefits of further testing in order to know more about the etiology, the prognosis, giving information for preparation and recurrence risk... versus the potential challenges that further testing could now bring? Diagnostic tests can take anywhere from about 2 to 6 weeks to obtain results. And so unless a patient is going straight to a CVS at the start of the testing window, results may only be available mid to second ‑‑ late second trimester. For my patients in Texas, where we already know that they have to go out of state, it has become an evolving puzzle of one, where will they go, be able to go once results are available? Whether that be 18 weeks, versus 20 weeks, versus 24 weeks. And two, are those even feasible options for that specific family? As we know, there are SO many barriers to accessing abortion, whether they be financial, physical in terms of travel, and mental and emotional! And though I have not had the experience of being in a state with an abortion ban, I could imagine further genetic testing could put a patient in a difficult space if they are, or if their closest most feasible option may be a state with an abortion ban. Next slide, please.

So there are many parts of that equation that are out of our control as providers. I DO think that knowledge and education is key to making sure that our current and future providers can provide thoughtful and comprehensive reproductive care and be able to handle these challenging conversations. However, prior studies that have explored abortion knowledge of genetic professionals and other providers have found existing gaps. So, in a study by Graziani et al that explored the experiences of 160‑plus genetic counselors working with patients facing the decision of termination after 24 weeks gestation, approximately one‑third reported only having some or no understanding of the procedures, and three‑quarters noted that they had some or no understanding of federal abortion law. In a more recent graduate thesis study by Sanchez et al, which I was fortunate to be part of and hope will be published in the near future, all responding genetic counseling programs in the United States noted having some level of an abortion curriculum, but variability in clinical training was noted as a barrier by both program representatives and recent counseling graduates. Next slide, please.

In fact, I wanted to take the time to highlight one of the free responses received where a recent genetic counseling graduate, trained in a more restrictive state but ended up practicing in a more supportive state, noted their differences. So, the person noted that it's important to acknowledge that the difference in coursework and clinical work one trainee may experience from another IS based on the state that they are trained in. This person realized that they had never learned the basic concepts of abortion, basic steps or coordination of the procedure, and genetic testing of products of conception, and how to navigate psychosocial counseling around the topic.

I think this inconsistency in abortion education and training HAS been seen with other health care professions and other health care training. It is important to note that we have seen an increase in abortion education offered, and that recently graduating genetic counselors and other providers may have more experience with these evolving conversations. However, I do wonder if that increase is going to be more based in didactic and classroom setting education, rather than clinical experience, as that is likely to be significantly decreased. I will give a shout‑out for anyone looking for research ideas: I do think that further research is needed to explore the ethical impact of potential disparities in education and training. How does this legislation affect where students elect to receive their education and where they may choose to practice after? And how does that affect patient access and knowledge? Next slide, please.

To add to that point, I will say that we already know that many families do not have accurate understanding or information about abortion laws in their state. There have been a number of studies published. But! To kind of be in reference to Michelle's discussion earlier of the research that has been conducted in Ohio, I wanted to specifically focus on the gal low et al study. Next slide, please.

This study focused on reproductive‑aged individuals in Ohio during the six‑week abortion ban. Within the studied population, most participants did recognize that abortion was still legal at that time, but about 36% thought that abortion was illegal or were not sure about the legality status. Dem ‑‑ demographic information associated with the misconception of abortion being illegal were younger age, lower social economic status, never married or married status, and Black, non‑Hispanic race and ethnicity. Alarmingly, the proportion of respondents believing abortion was illegal actually increased from the first month of this study to the last month of this study! And I think that says a lot when we think about that with the upcoming legislation: that things may not happen overnight, and that there are gonna be periods of uncertainty. I don't think any of us here today are surprised to hear that those already vulnerable to disparities will have additional barriers to understanding their rights and accessing abortion care. Additionally, the legislation that was proposed in Ohio at this time did not include any enforcement mechanisms or reason bans, and it would be likely that such additions would cause even more confusion and perhaps patient fear in asking providers, family, and friends about their options. Given the enforcement tied to SB 8, I have had multiple families ask if they can even say the word abortion, or if that is even something they can ask about during a medical visit. I've also seen and heard many providers be unsure of what they can discuss, and worried about legal action.

So I think there are so many uncertainties to be based with the anticipated Dobbs decision. We are in a critical time point to discuss how we ensure the trust of the patient‑provider relationship, particularly for those part of vulnerable populations, in these discussions of abortion care. I will end on that note and turn it back to Kim for discussion. And thank you again to Sarah for having me be part of this discussion.

KIMBERLY MUTCHERSON: Thanks so much to, to both of you. It always feels weird to say "thank you" when I hear things that make me very sad and depressed? (chuckles) Um. But at the same time, the work is so critical.

So I wanna remind folks that you can post questions in the Q&A, and I will happily share those with our panelists. But I'm also gonna take moderator's privilege and ask a couple of questions myself.

So, one question that I have is about how the informed consent process might shift. And what I mean by that is: If you were in a state that says, for instance, you can't have an abortion because of genetic anomaly, would ‑‑ do you think that genetic counselors would feel comfortable, or whether it would be appropriate for a genetic counselor to say: You know, by the way, if you go to a clinic and you say the reason why you're getting this is X, they're not gonna perform the abortion for you. So I'm curious whether you feel like, one, those ‑‑ that's also a piece of the dilemma that might come up for folks. And if so, how do you think people would or SHOULD be responsive to that?

Aarti, you're unmuted already, so why don't you start? And then we can jump over to Michelle.

AARTI RAMDANEY: Thank you, Kim. And I think that is such a valid question. And I will say, it is something that our genetic counseling group really had to come to terms with in the beginning days of SB 8. Of how... do we respect the legislation that's there, but then still provide the best care that we can for patients, AND provide anticipatory guidance? And I will say, as part of our pretest counseling for so many patients, it is that question of kind of asking patients of... where they see them going with the result! And kind of what do those results mean for them and their family? And so I think that has really INcreased that question in the beginning, so that we can provide patients with appropriate guidance ‑‑ or... appropriate insight into what their options might be in the state, versus what other steps might need to be taken if they are considering those options in another state, too. And so I think addressing those on the front end is SO, so important. Just because we also HAVE seen patients where they were NOT informed of that prior to genetic testing, and unfortunately then are ‑‑ feel so helpless when they're confronted with that information later on.

MICHELLE McGOWAN: ...this is a great question. And I will share some responses to it from the data that we collected, where we had prenatal genetic counselors who were debating what would happen if a six‑week ban were to go into effect. The one that Aarti just described that would be proposed and signed into law, but has been blocked by the courts ever since.

So, on the one hand, there were some genetic counselors who said, well, I think there might be a lot less prenatal genetic testing! Available! If there's a six‑week ban. It just might not be offered up to patients as, as much as it is now. Which is quite striking. You know, that's like a very strong chilling effect that she was predicting. And on the other hand, there was... the other perspective that we often heard was the idea that, you know, the field of genomic testing and prenatal genetics is moving along at a rapid clip, and not necessarily in alignment with the law. And that it then presents an ethical dilemma for professionals working in this space, where that interface with both the technology and the law. And we heard prenatal counselors say it's going to present really strong problems for us, where there may be this really strong technological imperative to continue to use the technologies that are available to learn things about pregnancies that... are really valuable information for people, and then constraints around the kind of counseling that we give. So you know, they would say maybe there wouldn't necessarily be a change in the informed consent process, but there could be a really big change in the type of counseling that they give patients. And there was hand‑wringing! Moral distress that we heard! Over this prospect of having to tell patients, well, you know, WE know that this may be why you would be considering ending your pregnancy, but please don't tell anybody. They felt like that was deceptive, that it went against the tenets of their profession. And it made them feel like they were going to be in a really awkward position, in terms of their relationships with their patients ‑‑ not necessarily in relation to law. Which, I would argue they would ‑‑ they DIDN'T feel they needed to respect any of these laws? But rather that... you know, because they were outraged by so many of them. And yet, they knew they would be in a conundrum, like if some of these laws were to go into effect. And likely that they may face these conundrums in the future.

KIMBERLY MUTCHERSON: Thank you. So I wanna go to one of the questions that, um, was asked in the Q&A, which goes back to SB 8, which folks will remember has this really lovely...! Bountier hunt ‑‑ bounty hunter aspect to it, which essentially allows anyone who believes that they know someone who's either providing abortion or aiding and abetting...! Someone in GETTING an abortion, to be dragged into court, and sued, and possibly have to pay fines of $10,000 or more. And so the question really is about, you know, what are the implications of SB 8 and how it might constrain counseling? BECAUSE people are worried about their own liability! For providing ‑‑ for providing information under a law like that.

Aarti, do you wanna pick that one up?

AARTI RAMDANEY: Sure. And I ‑‑ (sighs) ...I feel like we would have a whole other Q&A to discuss all the things that have happened with SB 8 and how that's influenced counseling and care. I will say that... to Michelle's point earlier: Respecting, but then also assessing like legal concerns when we think about the laws that are going into effect, and how do we protect our providers? That all of these things really came into discussion when SB 8 was first introduced in September 2021. And I think we've seen counselors...! And their institutions! Kind of... appreciate the law differently, or understand the law differently in different contexts. And so I think that HAS caused a lot of ‑‑ sometimes discrepancy! Of what kind of care patients are receiving, and how much guidance they may receive about how to access abortion services outside of the state of Texas.

And I will say: To our extent, we were ‑‑ we did have a legal discussion with our full team to say, okay. We know that we can have to say that it is illegal in the state of Texas after six weeks gestation, but we ARE still okay to discuss out‑of‑state options and be able to facilitate some of that coordination, or just making sure patients know where to get to? However, I will say that we have also seen individual providers say I, I still feel uncomfortable, or I still think about, well, what if a patient does record me, or what if this DOES go somewhere from a legal angle? And then what does that mean for my ability to practice ‑‑ as well as for the institution to pay all those fees as well, too.

And so, I... I don't think there IS a clear‑cut experience, just because so much probability is dependent on where a specific genetic counselor is practicing and their own institution's interpretation of the law.

KIMBERLY MUTCHERSON: Michelle, I wonder if I can ask you the second part of this person's question, which is how do you think the professional field is responding ‑‑ or WILL respond ‑‑ to the political context, given historic efforts of genetic counseling to distance itself from the world of abortion? Which, you know, I would say even beyond genetic counselors, LOTS of folks! The fertility industry works really hard! To avoid being lumped in with abortion providers. So, what's your sense of whether this moment is going to, you know, lead to more connection or lead to folks being even more adamant that that's not what we do and we shouldn't be lumped in with those people.

MICHELLE McGOWAN: Yeah, that's an excellent question. I mean, if we think about the history of the field of genetic counseling, there was a strong desire not to be seen as contributing to a eugenic sort of ideology. And to this day, I think that this is really an important, you know, feature of the field. That genetic counselors don't want to be seen as trying to sway patients in one direction or another, about what decisions they should make with their pregnancies. My sense is that there is a stronger appetite among the profession now to... to take on this issue, in collaboration with other professional societies ‑‑ in obstetrics, in gynecology, maternal‑fetal medicine. We're now seeing the American Medical Association coming out, you know, very strongly. And my stance on this is that... this can no longer be a siloed issue. And I think there is a broader recognition now that... it's important not to leave this fight only to the owners and directors of abortion clinics! We have ample evidence of the fears that Aarti just described among obstetrician gynecologists, that they're worried about losing their licenses, they're worried about the legal ramifications of being in violation of existing laws. And it may have a real strong deterrence for them for pursuing providing abortion care in their own practices.

And so, you know, genetic counselors are positioned slightly differently: They aren't the ones providing the care, but they are in a position to provide information, and potential referrals, and potential warm handoffs. Right? And so, I would urge the profession to... to take seriously this role that they've long had? And to be more open and transparent about it. And my sense is that there is a strong desire to, to be more a part of these conversations than in the past ‑‑ with a recognition that there ‑‑ you know. This is, um, not an uncontroversial space to be in.

KIMBERLY MUTCHERSON: Thank you. The next question is, I think, a particularly difficult one, and one that we always have to talk about in this context, which is: how this country treats folks with disabilities, how we think about disability in the context of pregnancy and genetic testing. And the question really is, you know, what has been the experience in abortion‑restricted states with working with people IN the disability community on these issues of genetic testing? And making sure that those are voices that are a part of the conversation. And whether you have any sense ‑‑ or, actually, I won't ask the last part of the question, because I think that requires too much speculation. But anyway, how to deal with these questions of making sure that people with disabilities themselves are able to be a part of these discussions and help us think deeply about what it means to be a person living with disability.

Sorry. Aarti! Why don't you start, 'cause Michelle was just talking. Okay.

AARTI RAMDANEY: That's okay! And I ‑‑ I think this is such a crucial question to be asked. I definitely thank the attendee for bringing this up. And I think it's ‑‑ one, that we all... I think for so long, whether ‑‑ the abortion rights community and the disability community have always been told, oh, you're in conflict with one another, and that the two cannot exist harmoniously? And I think that is actually completely wrong! I think there IS a way for both groups to really function and collaborate together, to make sure that all patients can make the most informed decisions for themselves, too. I think when we know being in a restrictive state, one of the MOST important things that we CAN do is provide patients with ALL the information that they need to make an informed decision? And that includes giving light to the various different symptoms that a condition might have, and what that day‑to‑day also looks like, too. I think we've tried to work very much in connection with different disability groups ‑‑ different like patient advocacy groups, and different like family syndrome ‑‑ like. Facebook groups, in‑person groups; all of that? So that patients can really see the broad array of information that is available to them. I will say ‑‑ and Michelle might have more insight to this, too. I think as much as these two groups have been told to be in direct opposite of each other, that isn't true! We've heard a lot from many disability groups that this ‑‑ these decisions are not in line with what they want as well, either! And that they really do want the autonomy of choice to be there! Without sacrificing the support resources or needs of their communities.

MICHELLE McGOWAN: Yeah. Ah, that's... a great jumping off point for what I was going to say, which is that in Ohio, there were Down's syndrome advocacy groups that opposed the legislation. Which was called the Down's syndrome Nondiscrimination Act. And the opposition was around this question of values. So, who's ‑‑ if we want people to make decisions that are best aligned with their values and how they see optimizing their lives and their families, we can't foreclose one set of pathways. Like banning terminating pregnancies. Um. Certainly, there's a lot of evidence, you know, from... ah, other parts of the world that, you know, the more available prenatal screening is for trisomies, that the less likely we may see these populations in the birth cohorts. And to me, that speaks to a need for this more comprehensive approach to education of families, but also to structural challenges. So we recognize that people make decisions to ‑‑ NOT to continue pregnancies on the basis of information, or the lack of information, about what kind of supports will be available for their families and for their children to be able to flourish. And we know that there are some real structural impediments to being able to make a decision to have a child that is going to have a disability, and know that they'll be well cared for in this society and valued.

So I agree with Aarti that there's more opportunity for collaboration. And to draw from Black feminist scholars like yourself, um. You know, we have to think about the con‑ ‑‑ the continuum of, of the reproductive life cycle. And that reproduction doesn't end at birth, but rather continues through, you know, a child's life. And we want to make sure that people are making decisions and have the supports to be able to raise their children in supportive and safe environments.

KIMBERLY MUTCHERSON: Absolutely. And I just ‑‑ you know. I will just add to that that I think, you know, a huge part of this conversation as states start to make it harder, if not impossible, for people to get access to abortion is really demanding an expansion of our social safety net! Right? You can't force people to have babies and then say, hope everything goes okay with that! And also thinking about the fact that, you know, maternal mortality in this country is obscene! And so again! If you're gonna put people in a position where they are going to give birth, let's try to keep more of them alive. That would be a really lovely thing for us to do.

Um! Another really wonderful question: Do you have recommendations about what kind of documentation folks should be putting in their clinic notes to protect both patients and providers?

AARTI RAMDANEY: ...that is a very challenging question. And I apologize, 'cause I wish I could have something clear‑cut, but I ‑‑ I think it's gonna vary so much depending on what the state law... ends UP being? If there are changes in that state law over time? As well as what ‑‑ again, that person's institution recognizes the like legal interpretation to be. And so, if there's anything I can recommend, it's to have those open discussions, WITH legal, to really assess kind of what ‑‑ what THEY would recommend, what are kind of their interpretations? And how do we make sure that our notes are still... understandable to other providers, to patients, and that they don't necessarily mask the care that's being given? But are still within the confines of that state law.

MICHELLE McGOWAN: I would also argue for a more unified strategy of the professional societies here, though, to take a strong stance. That... you know, the practice of health care should not be decided by legislatures! State or federal!

AARTI RAMDANEY: Mm‑hmm.

MICHELLE McGOWAN: And. So, you know, I'm not a provider, I'm a researcher. And I would throw this back to the professional societies to come out with stances about how their professional autonomy would be impacted by, you know... contorting themselves to accommodate regulations that are interfering with their practices. To me, that seems like the best way to promote patient autonomy is to ensure that they can have open relationships with their providers, and that providers aren't speaking in code to avoid surveillance. By their institutions or by their states.

KIMBERLY MUTCHERSON: So I, I have another sort of thought about the, um... the information question. And this sort of goes back to what Aarti was saying in the beginning, about, you know, having people come in ‑‑ or, maybe it was Michelle, I'm sorry. Somebody, one of you was talking about folks trying to educate themselves on what the moving targets are, of the law, in their particular jurisdictions. And I think another sort of difficulty here is figuring out: Do you say nothing, because you're not sure? Do you try to keep up with everything? Right, so that you can give people accurate information ‑‑ even though that information can be changing, from day‑to‑day. Or do you sort of say, well, I ‑‑ I'm not a lawyer! Right? And I'm not an abortion provider! So I can't be the person who tells you, you know, what the rules are today, because I don't wanna take responsibility for that. And I think that THAT puts people in a really... difficult set of circumstances, as well. And I don't know if either one of you wants to say anything in response to that before I have to give it back to Maya so she can finish this up for the day.

MICHELLE McGOWAN: I'll just mention that, you know, the... the genetic counselors that we consulted with for this project all said that this is an inordinate amount of work for them.

KIMBERLY MUTCHERSON: Mm.

MICHELLE McGOWAN: And they... it's work that they feel like ‑‑ and time, that they feel like they should be spending working with their patients! Instead of trying to figure out what the current state of the law is, and how it applies to them. And so that's just another... you know, I think that the more that resources can be made available TO the profession, to help guide them, so it's NOT so localized to the level of the institution?

KIMBERLY MUTCHERSON: Mm‑hmm.

MICHELLE McGOWAN: I think ‑‑ I think the better it will be for providers who ‑‑ you know. Because it could exponentially increase their workload, if it becomes as dynamic as is projected.

KIMBERLY MUTCHERSON: Yeah.

AARTI RAMDANEY: And I would agree with that. I will say being in Texas, it's ‑‑ we've unfortunately had to joke that we feel like a lot of us NEED law degrees to keep, like, understanding the changes in legislation and where we're ABLE to send patients. So, for example, we are very close to Oklahoma! So that was a state that we could refer patients to. But then with changes, we had to all of a sudden kind of reroute as well, too? And I think it's important, to Michelle's point of... these things should not be localized to necessarily a certain institution or a particular state. I think we should call upon national organizations to make these things more standardized, and to provide a more united front. I will also say that even though I think a lot of the context has been around counseling BY genetic counselors, not all patients SEE a genetic counselor! And so not all patients might be able to have that discussion? And I think for other providers to be able to handle that amount of work, and kind of assessing different legislation, is also going to be a very big ask, and is probably going to lead to a lot of provider burnout or other challenges!

KIMBERLY MUTCHERSON: Great. Thank you both. This was really ‑‑ it was wonderful for me! I hope it was wonderful for the audience, as well!

MAYA SABATELLO: Thank you SO much. I ‑‑ your presentations and moderation and the questions were absolutely wonderful. Thank you for this informative session. For those of you who can, please join us in our post‑event discussion. The link is in the chat. And we look forward to seeing you in July for our ELSI Friday Forum on the Legal Challenges to Newborn Screening Research. Also, you will receive a post‑event survey. So I encourage you to complete this, as our organizing committee takes your comments and suggestions very seriously. It has informed us on how to improve the forum and brings new topic and speakers to you. So please fill that out.

I wish you all a wonderful weekend. Thank you very much again to our panelists and our moderator. And we look forward to seeing you in the post‑forum event. Thank you, everyone.