

TRANSCRIPT - TECHNICALLY OPTIMISTIC - SEASON 2 - EP. 4

RAFFI VO: Earlier this season, you heard me speak with Ethan Zuckerman. He's a pioneering technologist, the one-time inventor of the pop-up ad, and currently a professor at UMass Amherst.

He told me a story that's pretty important.

ETHAN ZUCKERMAN: I had the pleasure of interviewing Janet Vertesi, who's a professor at Princeton, who made the decision to keep her first pregnancy and then her subsequent pregnancies off the internet.

And this required all sorts of complex things, including paying for goods from online stores using prepaid credit cards. It eventually got her investigated for terrorism.

RAFFI VO: Janet used a private web browser called Tor to search for baby products. She kept references to her pregnancy off social media, and she asked her friends and family to do the same. And yes, she and her husband used prepaid cards, or cash, for their baby purchases, to try and stay off the radar of online trackers. But this put them *on* the radar of law enforcement, because their local pharmacy had a policy to report excessive gift card purchases to the police.

Janet was doing all this to show the immense, individual work it takes to truly safeguard your personal data. And this was ten years ago.

ETHAN ZUCKERMAN: Right now, being privacy conscious forces you into these incredible convoluted ways of interacting online. And as a result, it appears to be something that you would only do if you were really truly obsessed with these things.

RAFFI VO: But Janet's experiment also revealed something shocking about the way the data economy affects pregnant people.

Here's a clip from her appearance on Ethan's podcast, *Reimagining the Internet*.

[CLIP] JANET: *I had been very concerned about what I was seeing in the space that we were calling big data, big data and privacy. In particular, the kind of convergence of people's data sets to produce insights about them, but also to target them for advertising. And the fact that I had learned that a pregnant woman's data—once a pregnant woman has been detected—that data is so valuable. That targeting data is so valuable. It just moves, right? If you can sell that data at a top dollar to someone else who's going to sell Pampers or Huggies to that woman, that woman has lost control over where their data goes.*

RAFFI VO: You might have also heard a story, from back in 2012, about how the retailer Target knew that one of its customers was pregnant before her father did.

CLIP: The Target predictive analytics gurus identified what they described as a pregnancy prediction score.

RAFFI VO: Here's Professor Charles Wheelan, author of the book *Naked Statistics*, speaking in 2013.

CLIP: The New York Times Magazine reported a story about a man from Minneapolis. The man was irate because his high-school daughter was being bombarded with pregnancy-related coupons from Target. The Target statisticians had figured out that his daughter was pregnant before he did.

RAFFI VO: As we've been talking about this season, a crucial component of the data economy is that consumers are subjected to all kinds of digital surveillance. Through cookies, tracking pixels, data brokers, and more the default experience of being on the internet today means you're being tracked.

And when it comes to pregnant people, even *potentially* pregnant people their data is very valuable to companies doing the tracking.

But this data can also put people at risk.

CLIP Anchor: Poppy and Jim, the Court issuing that landmark ruling that this nation has been bracing for, and the Supreme Court has overturned Roe v. Wade. That they have eliminated... [Tape ducks under]

RAFFI VO: In June of 2022, the U.S. Supreme Court issued their opinion in *Dobbs versus Jackson Women's Health Organization*. The ruling overturned *Roe v. Wade*, the 1973 decision that had grounded the American people's right to an abortion in the Constitution.

CLIP: Karen Finney: It's not just about abortion. It's about the fundamental right to control your own body.

CLIP: Protestors: Keep abortion safe and legal! This decision must not stand!

RAFFI VO: When *Dobbs* was decided, 13 states had already passed so-called trigger laws, which criminalized abortion either immediately, or shortly after this decision came down. At least nine other states had laws banning abortion on the books from *before Roe v. Wade*, some of which became enforceable again in 2022.

But the world is very different than it was in 1973. Over the past fifty years, technology has radically changed the landscape of not just reproductive health care, but healthcare in general.

For one thing, now we've got electronic medical records, which can be transferred between different healthcare providers. But they're also subject to hacks or data breaches.

But really, your phone's location history, your Facebook messages, the items in your online shopping cart, your voice memos, your texts, all this digital data can tell a story about your pregnancy, or your friend's pregnancy, and none of these things existed in pre-Roe America.

CLIP: Anchor: When the Supreme Court struck down Roe v. Wade, privacy and abortion rights advocates both warned about this very thing: authorities prosecuting abortion-related criminal cases relying on personal, digital data.

CLIP: Prosecutors could go after people seeking an abortion by subpoenaing data, linked on fertility apps, period trackers, and on internet searches.

SUE DUNLAP: I think part of what we don't understand as a society, um, is the nonstop level of threat from every direction.

RAFFI VO: That's Sue Dunlap, the President and CEO of Planned Parenthood Los Angeles. She is on the frontlines, working to provide access to reproductive care, including abortions.

SUE DUNLAP: I've worked for Planned Parenthood for 25 years, all over the country, and I've seen a lot of things I didn't want to be true about our world. In my heart, I wish for a different world. The year before Roe was overturned, we had a pretty clear sense that Roe would be overturned. And time and time again, I met with different legal groups and was given technical arguments as to why Roe couldn't be overturned. And what I actually think is that I, in my role, didn't do enough to stand up for what I know to be true.

I know pregnant people, women, are increasingly being criminalized, victimized and lied to. And so when I think about technology as a piece of that, what I want is a system that helps women and protects women. And I haven't seen that system yet.

RAFFI VO: It's not super common to hear a tech podcast talk about abortion. But it's relevant and important because reproductive healthcare in America right now is, in some part, about data.

In the surveillance economy, we already know that our data is being used to track and profile us. But for many pregnant people in America, their data is now being used to criminalize behavior that was Constitutionally protected one day, and illegal the next.

And could this be a preview of what's to come? Could more and more of our data be sort of weaponized against us?

Thinking about things in those terms, the landscape can seem pretty grim. But in this episode, I'm talking to people who are working hard to *protect* the rights of women and pregnant people in America. And they are doing courageous stuff in order to get past this gloom.

Look. No one's saying it's gonna be easy. There are lots of fights still to come. But they're up for the challenge. Are you?

I'm Raffi Krikorian. And from Emerson Collective, this is Technically Optimistic.

[THEME MUSIC]

SUE DUNLAP: I think we're living in a moment where women, pregnant people, are being criminalized just for being pregnant, period.

RAFFI VO: To Sue Dunlap, part of what the Dobbs decision did was expose something about abortion and reproductive care in America that had been true even under Roe v. Wade.

SUE DUNLAP: Sexual and reproductive healthcare, most notably abortion, is outside the healthcare system and is treated like it's not healthcare, and that's something we have to be mindful of, too, as people who are seeking to sort of solve access issues.

RAFFI VO RT: I imagine this might be a really big question, but Sue, in your opinion, why is reproductive care like that in America? Why is it outside the system?

SUE DUNLAP: Because sexual and reproductive health care is stigmatized. Because today in our country, abortion is being criminalized.

I think we're in a moment of great change, and I don't think we know how this moment should work. If you don't have the protections of a Roe v. Wade, if you don't have federal protections for abortion access. If abortion and sexual and reproductive health care exist outside the health care system, I don't know how to tell you how it should work.

RAFFI VO: I should say, I know Sue personally. I'm on the board of Planned Parenthood, and we've spoken a lot about the state of things, and how urgent everything feels right now.

But, when I talked to her for the show, I pitched a conversation about *technology's* role in reproductive rights. And it's not that she wasn't interested in talking about technology. It's just that she's skeptical about putting too much faith into it. She's worked too hard, and she's seen too much.

SUE DUNLAP: I find myself being very regressive when it comes to systems. We have to have redundancy, we have to have workarounds, we can't have a single point of failure. So when I was thinking about electronic health systems, I am loath to live in a world today where there's an interdependence and a vulnerability and, and when I think about data sharing, that's what I think of.

RAFFI: Can you give me a lived experience that you've been having of what women are actually going through right now?

SUE DUNLAP: Yeah. One story that for me, and I've, there's, there's so many stories that could break your heart. This one is a patient from Texas, chronic health condition, traveling here for an abortion, here being Los Angeles, so from Texas to Los Angeles, Texas to California, and we asked her, or her most recent blood work, and what she shared was that, the second she had even a whisper, an inkling that she might be pregnant, she stopped going to any doctor whatsoever, even as she had this chronic health condition that needs to be regularly managed and monitored because she doesn't want any record anywhere in any system in Texas that could suggest that she might be pregnant.

Now that, that would be true on paper. That, that's not specific to technology as opposed to on paper. But when we think about what that means in the context of technology, which is what she was imagining, it's horrifying to me.

I just don't live in that world today and nor do the people I see traveling across state lines for what we know is very safe healthcare, but that is criminalized, marginalized, and increasingly creating victims.

RAFFI VO: In the United States, even before Dobbs, people seeking abortions faced unique challenges. Despite the right to an abortion being enshrined in the Constitution, some states still put plenty of obstacles in the way.

And now, without Roe? There are some terrifying new obstacles.

SUE DUNLAP: One of the early data points in this post Roe era tells us that one in three women who are pregnant or seeking abortion who find themselves in the criminal justice system by way of that, that pregnancy, are essentially turned in by healthcare professionals or medical social workers.

So what I worry about when I try to balance what patients need in the moment and the potential for long term consequences and even criminalization is it's, there is no good answer, right?

RAFFI VO: When you criminalize abortion, you are criminalizing the people who seek abortions. It is a staggering coming together of health care and the criminal justice system. Who is out there who could even be in a position to try and tackle this?

MELANIE FONTES RAINER: I'm Melanie Fontes Rainer. I am the director at the U. S. Department of Health and Human Services Office for Civil Rights.

RAFFI VO: Aha.

MELANIE FONTES RAINER: For anyone paying attention, I don't think anything that's happening right now is a surprise, right? I think a lot of this was highly predictable. And so I think in some ways we've been able to try to prepare as much as we can, but there's a deficit of information when it comes to do people even know that we exist.

RAFFI VO: If you've never heard of the Office of Civil Rights that's inside the U.S. Department of Health and Human Services to be honest, I hadn't either.

MELANIE FONTES RAINER: Every single federal agency has a office for civil rights. Um, we are the second biggest one.

Our office is unique to any other civil rights office because we don't just do civil rights, right? So civil rights is a heavy mandate. It's a big lift. Like non discrimination and health programs and activities, making sure people are treated properly and getting their entitled benefits.

Because we're thinking about: What does it mean to be discriminated against because you're pregnant or what does it mean to now be targeted because of who you are and have your data targeted because of who you are and the kind of health care you're seeking and where you live?

But we also do privacy under HIPAA. We are the only federal office that does both of those things.

RAFFI VO: HIPAA is the Health Insurance Portability and Accountability Act.

It first passed in 1996. It was a massive effort on the part of the federal government to do some rulemaking around personal health information, electronic medical records in particular.

You might know it from your own doctor's office. It's HIPAA that grants U.S. patients the right to view their own medical records.

MELANIE FONTES RAINER: So first, if you Raffi sought to get your own medical records from your provider, you have a right under HIPAA. It's called the HIPAA right of Access provision. You could go in and for a reasonable cost and a reasonable amount of time, your provider must give you your records. So that's like a tenet of HIPAA.

RAFFI VO: It's also HIPAA that says health care providers have to alert the government if patient data is ever compromised.

MELANIE FONTES RAINER: A hospital system, a dentist, an insurance company, they're required to file a breach report and disclose that to the U.S. Department of Health and Human Services so that the public can know when these breaches happen.

Those are the rules that protect your protected health information from impermissible use and disclosure, meaning, um, did somebody have a permission to use and disclose this data in the first instance? Are they protecting it? Things like cyber security. We have a significant role in enforcement here on whether or not there's been a breach.

RAFFI VO: Back when the law passed in 1996, Congress gave themselves three years to come up with a set of national security standards for electronic health care information, as well as a set of privacy standards for protected health information.

CLIP: President Clinton: Every American has a right to know that his or her medical records are protected at all times from falling into the wrong hands. And yet more and more of our medical records are stored electronically.

RAFFI VO: That was good. It would take the pressure off the states, and introduce a framework, not only for privacy, but for what to do when privacy was violated.

CLIP: President Clinton: Today with the click of a mouse, personal health information can easily and now legally be passed around without patients' consent. I am determined to put an end to such violations of privacy.

RAFFI VO: So in 1999, President Clinton announced the first version of what would come to be known as the HIPAA Privacy Rule. Although it wouldn't get finalized until 2002. And it wouldn't go into effect until 2003. And it would be significantly modified by the HITECH act of 2009. As well as the HIPAA omnibus rule of 2013.

I mean, okay. Even by modern Congressional standards, this is a *really* confusing patchwork of laws. But the HHS Office of Civil Rights has a specially designated role in the HIPAA framework.

MELANIE FONTES RAINER: And so we enforce and implement HIPAA, the HIPAA privacy, security and breach notification rules.

The HIPAA Privacy Rule gives permissions, and those permissions means that covered entities, whether it's a health insurance company or health provider or pharmacy, they have discretion as to whether or not they believe that the permission is being met and whether or not they disclose the protected health information.

RAFFI VO: Even if you know about HIPAA, you probably have at least a few misconceptions about it, according to Director Fontes Rainer.

MELANIE FONTES RAINER: I think there's a lot of misinformation about HIPAA in the first instance, whether it's to doctors and hospitals or patients. And I have been told from people, right, you know, Oh, well, My HIPAA protects me for X or HIPAA protects my data on my phone or HIPAA protects me when I do X or I'm going to get my records because of HIPAA and some of that is true and some of that isn't true.

We all do everything on our phones now and I think a lot of people have a very unrealistic expectation of privacy and expectation of protection when they think it's just, oh, it's my medical information, so it's protected, right?

RAFFI VO: *Not* right, unfortunately.

MELANIE FONTES RAINER: There should be a business associate agreement in place so that data is protected. But oftentimes there isn't. So oftentimes you may be using some app on your phone that is not a HIPAA covered entity. It's not a business associate agreement. You're just using it. And so you are making yourself exposed.

RAFFI VO: HIPAA makes many concrete requirements about how health care providers have to treat medical records. The same is true for all sorts of private companies in the healthcare space. That's the function of these "business associate agreements" that the Director just mentioned.

But HIPAA makes no provisions for technology companies.

MELANIE FONTES RAINER: And so one of the first things my office did last summer. Was we put out literally, here's how to take this into your own hands, even when HIPAA doesn't apply,

right? Like basic things, right? Turning off, tracking things, checking off geolocation, making sure you're not storing protected health information on your phone, on your tablet, on your devices in the first instant.

Don't store it into the Google Cloud. Don't store it into the Apple Cloud, um, because these things can be searchable, identifiable, and sometimes they're not protected.

RAFFI VO: So this is the problem, and it's twofold. HIPAA goes so far, but falls short of protecting many sources of health care data for the twenty-first century American. And, in a landscape without the protections of Roe v. Wade, it also became clear that HIPAA had huge gaps in it when it comes to reproductive healthcare.

And when you take those two issues together? Then you're at the intersection of data privacy and abortion rights.

SUE DUNLAP: I'm going to turn again to a story here.

RAFFI VO: Again, here's Sue Dunlap of Planned Parenthood Los Angeles.

SUE DUNLAP: We recently had a patient here in Los Angeles who had started in Georgia, then went to South Carolina, got sent back to Georgia, then went to Florida, then from Florida to Los Angeles, um, all because there were various abortion limitations and bans.

The very first thing when one of our doctors came into my office to sort of explain what had happened, he said, "She came with a stack of papers that made no sense." Would having had one seamless electronic health record have made her experience better?

In a perfect world, yes. But I can also tell you that what was contained in those papers was also informed by fears around the limitations in each state. So, what a doctor in California might expect versus what a doctor or a practitioner in a state where abortion is becoming criminalized might be able to offer are also very, very different.

So again, I'm stuck in this in between where I can tell you what we aspire to and want isn't here today. What should we do now? I think we have to live in both. I don't its a this is a solution! Health records! I think that's naive.

Our patients live in a different world, and that's exacerbated by dramatic differences across geography, which frankly are only going to become more intense. It just starts to create a dynamic that is not going to work and isn't compatible with the beautiful vision of shared electronic health records, which is that patients can travel and they can get the best care possible. And so an electronic health record starts to become the path to transfer those disparities.

RAFFI VO: Sue reminds me that in real life, tech doesn't live in a vacuum. In a world where your own data can be weaponized against you like this, what might seem like a simple, obvious solution to a technologist, like electronic health records, becomes a huge social issue. An emblem of the loss of autonomy and surveillance.

And, not just surveillance. For many Americans seeking reproductive care, simply visiting the doctor generates a dystopian digital scarlet letter. It could lead to your being fined, or jailed or to an awful, self-destructive cycle, where in order to avoid getting arrested, you avoid seeing a doctor.

Post-Dobbs America is a place where people have to choose: Should I risk prosecution? Or should I risk getting sicker? And for pregnant people, the choice is even starker. States with restrictive abortion laws have made it so your data can very literally be the difference between life and death. That's post-Dobbs America.

But, Melanie Fontes Rainer is trying to steer us out of this nightmare. And she's trying to do that by fixing HIPAA.

MELANIE FONTES RAINER: So in this space that we live in now in post-Dobbs, a lot of reproductive health care providers, reproductive health care clinics, OBGYN facilities, they are very aware of that. Trying to misuse data, trying to track women, going on fishing expeditions, none of this is new. Those kinds of providers are very familiar with the landscape and they know the law.

Oftentimes before you have surgery, what do they do? They give you a blood test to make sure you're not pregnant, right? And now you have a medical record, whether or not it's related to your reproductive healthcare, that now affirmatively states whether or not you're pregnant that someone wants to have, that someone could track you.

And so those are the instances I worry about because your medical record through your electronic health record can be everywhere, right? I've had people tell me, you know, uh, we had a patient, she went to California for an abortion when she went back home to state X. The provider said I see you had an abortion in California, right? And now they may hand over those records. And so, you know, that's why we have proposed a rule to actually take it a step further. We have a proposed rule that will actually prohibit those disclosures in the first instance.

RAFFI VO: It's called the HIPAA Privacy Rule to Support Reproductive Health Care Privacy. Yeah that's right—privacy's in there *twice*. And when we recorded my conversation with Director Fontes Rainer, it was just a proposal. But on April 26th, it became official.

CLIP: Thank you for joining us, uh, to discuss today's major announcement from the Department of Health and Human Services.

The new rule protects patients *and* providers, because it basically says, if reproductive health care was given or received in a state where that care was legal...

CLIP: Melanie: *...that information about that health care cannot be used or disclosed by that healthcare provider or health plan for an investigation to impose liability on an individual or the provider.*

CLIP: Sec. Becerra: *There is one thing Dobbs did not take away, and that is the right of Americans to their privacy.*

RAFFI VO: That's HHS Secretary Xavier Becerra. He's at a press conference announcing the new rule, with Director Fontes Rainer at his side.

CLIP: Sec. Becerra: *We took action the moment the Dobbs decision became public, and we're not stopping.*

MELANIE FONTES RAINER: The idea, right, that me as an individual, as a human being, that I can't travel somewhere to where the healthcare is lawful to receive lawful healthcare on my dime, that that's not legal and that my state thinks they own me. That is bananas.

RAFFI VO: This does seem bananas. And completely unfair. Through no fault of their own, Americans seeking reproductive healthcare find themselves restricted, monitored, and under the threat of prosecution.

And because this seems so unfair, and so outside their control, it's strange that the best data privacy advice we have for them is just strong encouragement for people to "take control" of their data themselves. We seem to be passing the buck. We're not so much helping them, as telling them to help themselves.

And, as we talked about at the beginning of this episode, when we heard about Dr. Janet Vertesi's experiment to keep her pregnancy offline, opting out of mainstream internet services can lead you to some strange places. And is itself sometimes seen as suspicious.

But, Director Fontes Rainer maintains that, when it comes to data privacy, you are your own best resource.

MELANIE FONTES RAINER: The best advocate for my own privacy is gonna be me, right? No one's gonna care more about my privacy than me. Within the healthcare space, we know that a lot of healthcare providers are using web tracking technologies to better understand their patient consumer populations.

And in those web tracking technologies, we have some authority. And we have reminded providers in particular that if you're going to use these types of technologies, take steps to be compliant with HIPAA, making sure and first and foremost that you have a business associate agreement, which is basically an agreement between Google, Meta pixel, these web tracking applications and the hospital so that if there is a breach, if there is an impermissible use or disclosure of that data, it's protected, because if it's not, then those providers are just exposing individual protected health information, which is not compliant with HIPAA.

I have limited jurisdiction. So to just like put a disclaimer, I have limited jurisdiction over that kind of data, right? So like, I can't always do something.

RAFFI: Can I just try and make this more concrete for the people who might be listening, Director? Are you effectively saying, don't use these apps? Is that, is that basically the message I should take away?

MELANIE FONTES RAINER: I'm saying you should not be storing protected health information on your phone, in a Google app, in any sort of, you know, there was a lot of attention on period trackers when Dobbs first happened, right? And a lot of steps were taken to try to get those individual apps to change how they were tracking data. But, we know that there are gaps in the regulatory authority and enforcement.

RAFFI VO: Gaps big enough for...apps, I guess.

***CLIP: Anchor:** Fertility and period tracking apps have some of the most sensitive reproductive information.*

RAFFI VO: The new HIPAA reproductive privacy rule does a lot to protect people who receive out-of-state care. That woman who traveled from Texas to California doesn't have fear that the results of a blood test might make it back to law enforcement in Texas. That's huge.

But the data collected by birth control apps? Is still potentially...dangerous.

***CLIP: Expert:** There is no difference in the data from your reproductive choices than the pair of shoes you looked at online. It's treated exactly the same in the law right now, and that's what the problem is.*

KEVIN WILLIAMS: Leading up to Dobbs, we have been talking a lot at Planned Parenthood in and around making sure folks feel educated around what was changing within certain states.

RAFFI VO: Kevin Williams is the VP of digital products at Planned Parenthood Federation of America, where he's worked for over a decade.

KEVIN WILLIAMS: Over one in three women plus many more folks that identify as trans and non-binary are without access in their states. And so obviously that is very, very important for us to get ahead of. And we've had to really be progressive and think how to take users through this very complex matrix now of what the laws are and where access is, and it's very confusing. It's a very challenging process.

RAFFI VO: Kevin and his team have been doing digital outreach in the face of two overlapping challenges: the suddenly-remote health care environment of the COVID pandemic and the confusing, restrictive landscape post-Dobbs.

And, as both of these events led more and more patients to seek health care information online, he knew that Planned Parenthood had to be exceedingly cautious in how it treated personal health data.

KEVIN WILLIAMS: So birth control and period tracking seemed like something for us to explore.

RAFFI VO: Planned Parenthood's own period tracking app is called Spot On. And it's been around in some form since 2016.

KEVIN WILLIAMS: From the beginning, I'll just say privacy and security has always been an area of focus for us. We believe that your personal health care data should never be used against you. We don't sell data. It's very important for us, even at the ideation and design stage to be thinking about that.

We don't collect information and sell it for advertising purposes. We don't collect the information, store it places. And I think that is the common industry standard of collecting that information. And so what was interesting was when all of the noise in and around concerns around privacy came up, there was a lot of focus on period trackers and folks were deleting their apps and we had to spend a lot of time educating people around understanding what we were doing was different than some other period trackers.

RAFFI VO: Planned Parenthood's app stores data locally, on your phone, rather than in the cloud.

KEVIN WILLIAMS: At Planned Parenthood, we speak a lot about how important privacy and security is to us. And so I think in a lot of ways, users and communities expect us to show up in this way. We've focused on thinking about accessibility, thinking about how we educate people to be empowered. I think that privacy is a top priority for us, and we stand by that.

RAFFI VO RT: Okay so you've been talking about how some of the values of Planned Parenthood, like transparency and data privacy, make it into your work as a product

designer. Which makes me wanna ask you, like, how do you think about accountability here? As a developer, but a developer in this particularly urgent space?

KEVIN WILLIAMS: It's a good question because we've been talking a lot in and around accountability as well. There's a real challenge on what accountability we have as an organization providing care as a trusted brand there to support people. And then also holding big technology accountable as far as educating people on how to use these fancy devices that everyone has now that are, you know, have the most sensitive information that they have available.

So when our team comes together thinking about what we should build and design, I mean, first and foremost, we work very closely with our information securities team. Our general counsel and legal advisors and folks are brought into that process right away in the beginning so that we are thinking bigger than just the moment. We're trying to be more thoughtful about what that idea is going to look like in execution and iteration over time.

You know, there's so much conversation around weaponizing of data these days, and there's a lack of trust. And so positioning ourself as a trusted resource has been really important to our social media and communications team. Just because there's just a... You know, it's next level out there right now. If I had to be honest, yes, it is a Wild West right now.

RAFFI: Yeah, it's the Wild West. Totally is.

Kevin Williams: It's kind of crazy. We've become so dependent on big technology. We really need to find a way to use this data for good.

RAFFI: Yeah.

KEVIN WILLIAMS: I think there is a lot of noise in and around the exploitation of data, but there's some real societal shifts that need to be observed. And I think part of the challenge with that is what information is being collected, where it's being stored, who's monitoring it, how is it being exchanged in between and across organizations. And I just would really like to have more conversations about that.

RAFFI: Yeah, yeah. I mean, I feel like the path out of this insanity is for a lot more of us to be talking about it as opposed to just sort of try and navigate around it.

KEVIN WILLIAMS: Yeah.

RAFFI VO: We're gonna keep the conversation going after a short break.

[MIDROLL]

RAFFI VO: Welcome back to *Technically Optimistic*, I'm Raffi Krikorian. We are talking about data, privacy, and data privacy, and the intersection with reproductive health care in a post-Dobbs America. And we have been hearing from people who have been finding ways to help.

Like Director Melanie Fontes Rainer, of the HHS Office of Civil Rights, who led a charge to amend and expand HIPAA. And Kevin Williams, VP of digital products at Planned Parenthood, who built a period tracker app that keeps data private.

Now, I want you to meet Amy Merrill. She is the digital director and co-founder of an organization called Plan C.

AMY MERRILL: The mission of Plan C is to normalize the self-directed method of abortion for safe self-managed abortion. So, it started as an idea, a concept, a question, *why don't we have access to abortion pills by mail in the US?* And it's evolved into a robust public health directory of information and creative campaigns where we suggest and introduce this information in ways that is understandable for people about ways that we can be reclaiming abortion and have agency over this reproductive health need as the country spirals.

RAFFI VO: Plan C's central operation is to facilitate getting abortion pills to people who need them, via the mail.

AMY MERRILL: Abortion pills are a reality in all states. That's kind of the core information that still so many people don't know. Even if you live in this state that has shut down abortion access and all these other ways, you still have options.

Pills are not a panacea, I wanna say too. There's always gonna be a need for in-person care. We advocate for all options to be available. That's also not the reality that we are living in in the US. And so our focus really is on expanding the notion of abortion, introducing this method of abortion pills, and self-directed care.

RAFFI VO: Plan C is also committed to providing resources and support for people who get abortions. That includes legal and financial support but also mental and emotional support, as well.

AMY MERRILL: Part of our acknowledgement at Plan C, is recognizing the transformative nature of this method –of the pills –and the opportunity for de-medicalization, the opportunity for ultimately the pills to go over the counter. And that recognition is grounded in a global context, that all around the world, people in other countries are already doing this by the millions. It's very common, it's more accessible, and it's known to be a method that is safe and effective, the World Health Organization calls it an essential medicine, all of that is already true.

RAFFI VO: As early as 2013, Amy began seeing abortion pills available through online medication vendors.

AMY MERRILL: We call them also websites that sell pills.

RAFFI VO: Many of them were operating overseas, unregulated, and pills would take weeks and weeks to arrive. So from early on, Plan C's goal was to provide a safer, quicker alternative to the "websites that sell pills."

And then...

AMY MERRILL: I mean, the beginning of the pandemic was a wild time for everyone. But we were sitting there at our computers going, "Oh my gosh, this is the moment." If there was ever a moment to introduce a new idea, which is accessing pills by mail, accessing care virtually, it's now but then the commerce routes started to shut down. The flights were stopping, things weren't being imported, and that became a mini crisis that suddenly shipments weren't coming into the US. And so simultaneously the providers were looking more and more closely at these restrictions on mailing the pills, questioning is this really the case? I mean, this is kind of crazy. Most of our other medications, the individual could go online to an online pharmacy and place their order and just do it. And this particular one has these antiquated requirements that it must be dispensed by a provider. It's very patriarchal, it's very medically unnecessary. And these inquiries were moving forward, providers were figuring out what they could do, and then the FDA rolled back the restrictions on medication abortion, on Mifepristone, which are called the REMS.

RAFFI VO: That stands for Risk Evaluation and Mitigation Strategies, which are the drug-specific guidelines put out by the Food and Drug Administration.

AMY MERRILL: So suddenly the REMS were lifted and these services popped up.

RAFFI VO: So it's just interesting to note again we're dealing with the convergence of two things here, which shaped the future: the permissive environment around telemedicine, due to the pandemic and the loss of privacy rights, due to Dobbs

AMY MERRILL: With the overturning of Roe, we absolutely updated our information to reflect the changing status, to help people understand the implications of the case and how it impacted state by state access to abortion. We are also advocating for some digital privacy recommendations on our site, or rather we're putting them right up top.

RAFFI VO: Plan C connects with online privacy organizations like the Digital Defense Fund in order to provide people with concrete advice for safeguarding their personal data.

Amy Merrill: So, we've spent many years gathering all of the best tips and best practices to present them to folks along the way.

So, using privacy enabled browsing. Browsers are typically always tracking people these days. It's gathering this history of what someone has done, where they've gone. There's another recommendation to turn off location services on your phone, that's something that has come up in the abortion issue of people having a record of their physical location. People are using encrypted text, so there's an app called Signal that folks are using for encrypted texting.

RAFFI VO: And real quick, in case you missed it, I talked to Meredith Whittaker, Signal's president, in episode 2.

AMY MERRILL: And oftentimes the providers are recommending that the patient download one of these encrypted services before going back and forth. So that's often baked into the telehealth intake process. There's also recommendations around email. There is a VPN, a virtual private network, that will hide your device's IP address. You know, it's not that—I don't wanna create the impression that all of these services out there are being nefarious. I mean, there's a lot we could talk about, of course, with tech and how data is being collected and used.

RAFFI: Mm-hmm.

AMY MERRILL: It's business, right? We think about this in terms of keeping a clean digital footprint. It's less about surveillance and more about someone who is coming after a person who had an abortion, who's trying to build a case and is trying to collect that digital footprint in order to make the case. So, you know, these are the steps that are recommended in order for that digital footprint to be clean and that person to maintain control over their experience.

RAFFI: I agree with everything you said, but at the same time, it seems desperately unfair that we have to make the care seeker do all this work

AMY MERRILL: Absolutely.

RAFFI: And that responsibility doesn't fall somewhere else. Like these are complicated things.

AMY MERRILL: Yeah, that was a big concern that came off after Dobbs. Every individual's assessing their own risk. It is an information game. The challenge is to get all this information out there to raise their awareness to the fact that there's a flip side to all of these technologies that track data.

I do appreciate the way that the veil is being lifted for us, I would say. Like, I appreciate that actually, yeah, these conversations are happening more openly about what is actually happening with these technologies. How can we learn more about how they function so that we

know what we're opting into. We have no idea what these apps are doing with our data, right? So now, I think we're in the process of swinging back to a place where we have an opportunity to be a little more conscientious about the way we're living our life with technology.

RAFFI: It's better if we make explicit choices not implicit choices. And I feel like with a lot of this tech, we've just implicitly chosen to use it and don't fully explore the trade-offs that we're making.

AMY MERRILL: Mm hmm. I love that description. Yep. There's ways that companies can step up. It's actually critical, I think, from a human rights lens, that companies that deal in data start to really assess the severity of the situation and take steps to proactively land on the right side of history with this stuff, you know, to protect their users from being caught up in a completely unjust, unconstitutional risk of a legal case against them for seeking their health care.

RAFFI VO: Take for example what happened in Nebraska, in the summer of 2022.

CLIP: Anchor: *A teenager and her mother are facing multiple charges after Facebook's parent company Meta turned over their private messages. Police say their messages prove the teen had an illegal abortion.*

RAFFI VO: Of course, tech companies have to comply with law enforcement when they really are in possession of data that's been subpoenaed. Privacy-centered apps like Signal get around this problem by using end-to-end encryption. They simply don't have the un-encrypted version of the messages sent on their platform.

But even Google, whose revenue is clearly tied to surveillance advertising, is making some adjustments. In December of 2023, they stopped storing location data on their servers claiming in a [blog post](#) that your location history is now stored right on your phone.

Now, some privacy watchdog groups question whether or not Google has really fully implemented this switch but the point is that companies really could "step up," as Amy's saying. Not only would this insulate our data from law enforcement, it would mean finally taking some responsibility off of individual care-seekers.

So tech companies can do better, but so could Congress.

REP. TED LIEU: Donald Trump campaigned on overturning Roe v. Wade, and he successfully did it by appointing justices who in fact overturned Roe v. Wade. Now states can do whatever they want.

RAFFI VO: This is Congressman Ted Lieu, the representative from California's 36th District.

REP. TED LIEU: And then some of these states have very aggressive Republican attorney generals who will prosecute people, uh, who seek reproductive health care, uh, who get abortions, and we don't think folks should be tracked on whether they went to a reproductive health clinic, or in some of these states who are looking at banning contraception, or who want to ban, you know, in vitro fertilization, we don't think people should be tracked if they go to an IVF clinic or if they go to a place that sells contraceptives. And that is the gist of the legislation we're trying to get through.

RAFFI VO: The bill is called the Reproductive Data Privacy and Protection Act and it was introduced this past March by Representative Lieu and four of his colleagues in the House.

REP. TED LIEU: Law enforcement can make demands of private sector companies in a way that they wouldn't be able to do if Congress passed a law saying you can't do that. So for example, even the tech companies, let's say, did the right thing in my view and said, Look, we're not going to give you the data on this user who visited an abortion clinic or reproductive health clinic and law enforcement gives them a subpoena. Well, you know what the tech company has to comply.

RAFFI VO: This proposed law would prohibit this. it would ban all sorts of communication about any individual's reproductive or sexual health, whether electronic or otherwise, from being used against that individual. These incidents we've been hearing about, when someone's Facebook messages or any kind of digital data is used to criminalize pregnant people? This bill would just outlaw all of that.

But there is one problem.

REP. TED LIEU: I frankly don't think it's going to happen in a Republican-controlled Congress. but if the house flips next term, then I think this legislation could get passed.

RAFFI VO: So, beyond reminding everyone that Election Day is Tuesday November 5th, what else can we do? Elections won't change the makeup of the Supreme Court. And there's a scary possibility that the *Dobbs* decision was only the beginning.

CLIP: Anchor: Today's arguments not only brought hundreds of protestors on both sides of the issue, it was also the first abortion-related hearing before the Supreme Court since the conservative majority eliminated the Constitutional right to abortion nearly two years ago.

RAFFI VO: This past March, the Court heard a case that has major implications for the availability of mifepristone, the medication that's used in nearly two-thirds of all abortions in the U.S.

A decision is expected in June.

AMY MERRILL: Absolutely we're keeping a very close eye on that case.

RAFFI VO: Amy Merrill of Plan C, again.

AMY MERRILL: The case is not about making Mifepristone illegal or taking it off the shelves, it's rolling it back again to these early REMS, these restrictions, so that it would be prevented from being put in the mail by US-based providers

And I wish I had a crystal ball, but I don't. We'll have to wait and hear.

RAFFI VO RT: Okay, this might be an impossible question to ask, but has technology been a net positive for reproductive health?

AMY MERRILL: Oh yeah, I would say absolutely. I am a bit of a tech optimist, but I think, yes, technology is allowing people to access information from anywhere they are. Technology is the reason this whole system of pills by mail is proliferating in the US. You know, it's that same system is making abortion pills available in all states for folks living in rural areas, for folks that don't have hundreds and hundreds of dollars to drive or go to an in-person clinic.

And so, yes, I think that is all net positive. And I also believe that technology is best thought of as a tool to get us where we want to go. We judge it as good or bad depending on whether it's serving our needs or whether we feel like it's controlling us or we're controlling it, you know, but it's a tool, it's our job to be stewards of it, to figure out what we want out of it, to regulate it when it's appropriate. It's looking ahead. You know, at Plan C we talk all the time about our vision of the future. I sometimes feel like progressive movements in the US are often just fighting against something that is going wrong or in the way or whatnot, but we really wanna be envisioning the future that we wanna build. And that's why I believe that this is a really hopeful conversation. That truly there's a beautiful vision here of liberation, of people being more in control, people having more autonomy over their well-being, their futures, their reproductive health and outcomes.

SUE DUNLAP: Someone just asked me the other day, sort of, they asked me very much along the vein of, of what you're hoping for or building towards, or, or sort of seeding in the world?

RAFFI VO: Once again, Sue Dunlap.

SUE DUNLAP: And, and my answer was, was like, that's not who I get to be anymore. I'm an administrator around abortion access and sexual reproductive health care in the years after Dobbs.

I don't feel like my place in the world anymore is to get to do that. I think what I do is I get us through this moment and that's where I'm cautious. It's not that I think I'm right. I think I'm a product of this moment when we see these regressive forces.

RAFFI: Yep.

SUE DUNLAP: I aspire to the world you're building or inspiring, but I don't think I'm gonna live in it for the duration of the next, let's say, ten years of my career. I just don't see it.

RAFFI VO RT: Well, at the risk of just sort of –Sue –putting that question right back at you: what is the system you want to work in? Like, are there things that could be set up, either via tech, or regulation that would make things easier for you or for the people you care for, or the people who will need care in the future?

SUE DUNLAP: I want to work towards a world where there's no such thing as a clinic or a system or a health center or a provider that's outside of the health care system. Today, we have things we call abortion clinics. Today, we have this thing we call Planned Parenthood. Today, we think about how do we keep women safe in the context of abortion access?

As long as we're having to talk about that outside of the healthcare system, outside of what sort of is right for you, your family, your body, your healthcare decision, I am fearful of solutions. Because to me, the solve is the solve that brings us into the system. When we talk about sort of information sharing in the context of, um, electronic health records, that's what that is.

It's the belief in a world where healthcare is fluid, where, where the interests of the patient come first. I live in the day to day reality that the world is not set up to put our patients first. In fact, the world is set up today to criminalize our patients. So I don't –as an administrator in this post Dobbs moment, I don't get to imagine –I don't think it's safe to imagine –that the system will protect and honor our patients and providers. It's my job to live in this space of compromise. And I love that it's your job to imagine a better future. I don't live in that one today.

In fact, the future I live in is, is a lot worse than it was a year ago.

RAFFI: Maybe we can get into a place where people like you and I are count –not counterbalancing but sort of challenging each other as we—

SUE DUNLAP: No, make me irrelevant. Make me irrelevant. Make, make my version of the world irrelevant.

RAFFI: I know this is not the world we want to live in.

SUE DUNLAP: Well, what I'd offer is that it's my job to ensure that we have layers of systems that provide for access in the long run, and what I'm increasingly aware of is that's not convenient, that's not easy, that's not the world we've been told to expect and aspire to vis a vis healthcare, but again, I want all the complexity. Because I think that's what's sustainable and, and that's not perfect, right?

And, and that is the world I hope for.

RAFFI VO: If you believe that you or someone else's health information privacy rights have been violated you can file a complaint with the Department of Health and Human Services's Office of Civil Rights. Go to [hhs.gov/ocr](https://www.hhs.gov/ocr).

And if you are seeking information about obtaining a medication abortion, or are looking for resources about the laws and availability of reproductive care in your area, visit [Plan Cpills.org](https://www.plancpills.org).

Next time on **Technically Optimistic**, we're talking about criminal justice.

How is surveillance technology being used by law enforcement? Or changing how the Courts interpret our rights?

And are new data-fueled technologies making us safer? Or the opposite?

That's next week, on **Technically Optimistic**.

[CREDITS]