

Ashley Nickels: Hi, I'm Ashley Nickels.

Casey Boyd-Swan: And I'm Casey Boyd-Swan.

Ashley: And this is the Growing Democracy Podcast— a space for citizens, experts, and advocates to create community together. Each week, we invite a guest to talk about civic engagement, governance, and how to grow our democracy.

This episode is part of a series on demystifying policy-relevant research. We're talking with academics throughout Northeast Ohio in a range of fields, from public health scholars, sociologists, criminologists, political scientists, and more. We're trying to unpack how expertise is developed, how research gets made, and why this is policy-relevant work. This is a collaborative series with support from the Northeast Ohio chapter of the Scholars Strategy Network. The Northeast Ohio chapter of the Scholars Strategy Network was launched in 2017 to bring together local, university-based scholars who are committed to using and sharing research to improve policy and strengthen democracy. If you want to be involved in the podcast and get behind the scenes content about each episode, head on over to patreon.com/growingdemocracyOH.

Casey: So this is very exciting, to have a fifth new series. I was a little sad that Series One, governing during the pandemic, was over. You know, it's like losing a project.

Ashley: It is. But this is our first kind of officially collaborative project, and that's really exciting, to see us venture into that space. And I'm really excited that we got to do it with the Scholars Strategy Network chapter in Northeast Ohio.

Casey: Yeah, and the cool thing was that it came out of— I mean, we already have done quite a few episodes with SSN members [like] Megan Hatch and Joe Mead, Meghan Novisky. Folks, check out their episodes from Series One. But also [in] Series Two, Kristi Andrasik came on and— we chat with the guests afterwards, once we're done recording, and she said, “oh my gosh, that was so fun!” And it really got me thinking about what is it that I do, and how do I share this with just normal people, non-academics.

Ashley: Yes. And I think it really kind of sparked a conversation between SSN

Northeast Ohio and us here at Growing Democracy, about how our mission to promote democracy [and] think about civic and political engagement, and their mission to provide jargon-free research to policymakers, journalists, and communities at large, really fit together in these really interesting ways. So it was really fun to be able to think through how this collaboration would work.

Casey: Yeah. I think we haven't necessarily focused on academics, just because there are lots of cool people in the community doing things, but there is something that academics do have to share. And oftentimes when they engage in this kind of public scholarship, they see it as not just spreading their research, but as actually part of their own civic identity. It's an opportunity, and sometimes like a mission, for them to engage civically.

Ashley: Yeah, and I think the crossover between SSN's interest in strengthening democracy, and our interest in growing democracy, are one in the same. So we're really excited to be able to bring guests on the show to be part of the podcast, to talk through their policy-relevant research, [and to] think about how that translates for them into their civic identity. And just as a note to our listeners, there will also be a video clip made available from these podcast episodes on the Scholars Strategy Network's Northeast Ohio chapter's YouTube page. So after you listen to the podcast, go check that out and see what scholars from across Northeast Ohio are doing.

Casey: And we can share the links down below in the show notes.

Ashley: Absolutely. Without further ado, I really am excited to have our first guest on this series with us here today, Dr. Sharona Hoffman. Professor Sharona Hoffman is the Edgar A. Hahn Professor of Law, Professor of Bioethics, and Co-Director of the Law-Medicine Center at Case Western Reserve University. She has written over sixty law journal articles and two books, focusing on health law and civil rights topics, with special expertise in health information technology. We're going to make sure that her website and her university bio are linked in our show notes, but for those of you that are listening, you can find more information about Dr. Hoffman at sharonahoffman.com and case.edu/law/our-school/faculty-directory/sharona-hoffman.

Casey: All right, so with us today, we're so excited, is Dr. Sharona Hoffman. It's great to have you with us today, thanks for being on the show.

Dr. Sharona Hoffman: My pleasure.

Casey: I know that we've read your bio already, and this is the part where everybody

goes, “well, you've already read her bio”— except for that, in my experience, you have a more interesting story to tell about who you are and [how] you got to be where you are. So, would you mind telling us a little bit about yourself?

Dr. Hoffman: Sure. So I'm a Professor of Law and Bioethics at Case Western Reserve University School of Law, and I'm also the Co-Director of our Law-Medicine Center. Before I became an academic, I practiced law for ten years, and the bulk of that was at the Equal Employment Opportunity Commission in Houston. I dealt with a lot of discrimination cases, and I got particularly interested in disability cases and the health issues surrounding that. So I actually went back to school and I got an LLM in Health Law—that's a master's degree in Health Law—and then I joined Case Western. And I actually also have a doctorate in Health Law from Case Western.

Casey: So you went back to school twice.

Dr. Hoffman: I did, though, the second time, I didn't have to take time off, because I just did it while teaching.

Ashley: That's amazing. I absolutely love— I mean, if anything, I think in the back of my head, I'm really inspired. I'm like, “I could go back and do something like that.” And it's fantastic.

Dr. Hoffman: And at any age— I did it at a pretty old age.

Ashley: That's wonderful. So today we're probably gonna spend most of our time talking about the health law work that you've been doing, though feel free to talk about all of the other work and background that you have experience in. But I want to ask about a recent research project that you've been working on that's focused on AI-related discrimination in healthcare. So my first question is, what is AI? And two, what inspired you to take on this project?

Dr. Hoffman: AI is artificial intelligence, and it's becoming quite commonly used in healthcare. AI works through algorithms, and doctors are using algorithms to help them make better diagnostic, and even treatment, decisions. So you might put in a patient's symptoms and it will suggest diagnosis. And that can become a problem, because sometimes the factors that it uses are things like gender and race, and sometimes it over-generalizes and it makes assumptions that might not be true for the particular person.

So how I got interested in this is, first of all, I've written a lot in the past about electronic health records and big data, so it was sort of a natural next step to get

interested in artificial intelligence, which is the latest and greatest. And some of the writing that I've done about health information technology has been with my husband, who is a computer science professor at Case Western. And so it was sort of natural to “marry,” so to speak, computer science and health, and come up with work on health information technology. And I've also written a lot about discrimination, and that grows out of my work at the EEOC— and so it was really fun to explore the intersection of these two areas of health information technology and discrimination with this very, very new phenomenon of AI.

Casey:

Now, I have a question for you because I think a lot of people think that discrimination comes from— I know economists see discrimination as that there's two different kinds of discrimination, and one of the kinds of discrimination is that people assume something about a certain group. And so if somebody belongs to that group, they may make assumptions about that individual, even though it's not reflective of the individual [and] it's just based on that person's kind of identity of who that person is. But I would think that people would kind of assume that, “well AI, these are computers, right? This is data making this decision. It's not subjective. It's objective.” So, how can there be discrimination when these are decisions or suggestions or work that's being made and done by computers?

Dr. Hoffman:

Well, that's an excellent question. So the type of discrimination we're talking about here is unintentional discrimination, as you've just very articulately explained. But that is a very serious part of discrimination theory; it's called disparate impact. So you have facially-neutral practices that often lead to discrimination, even though the person using those tools does not intend to discriminate. A classic example is IQ kinds of tests, or cognitive kinds of tests, which we know statistically disadvantage African Americans often, because they don't have the same kinds of educational opportunities or support opportunities that wealthier, more advantaged people will have. So it's not that they— if you take a test, you may have a low score, [and] not because you're not smart, or you don't know things, but because you haven't had the same opportunities as others.

Or in employment discrimination, there's a classic example: some employers have a no-beard policy, either for appearance's sake or because you need a ventilator for this job, or a respirator for this job. And that turns out to disadvantage African Americans, because disproportionately, they have a skin condition called pseudofolliculitis barbae, PFB, which causes them to suffer great irritation if they try to shave. And so you have a work rule that is totally neutral; the employer has no idea about this condition, but it really, really

disadvantages African American men who just can't shave.

So in the same way, you can have AI— you can have doctors using AI thinking that they are doing a good thing, that this will help them make better decisions, more accurate diagnoses. And very often it does. I certainly don't want to suggest AI shouldn't be used, or is a bad tool, but you have to be sensitive to the fact that it can be biased. It can compromise fairness.

Casey: Yeah, absolutely. I really appreciate that answer. And the other thing that I thought of, naturally, was women's experience of heart conditions, that they look different than men. And when we don't necessarily focus on a group—certain groups—oftentimes these conditions may not be known or may just kind of be swept under the rug.

Dr. Hoffman: Well, that's a perfect example of AI bias, for example. So when you develop an algorithm, you train it with information— you train it how to recognize heart conditions, or heart disease, or cancer, or whatever. But if your training data—if that data you are feeding it to make it learn how to operate—is from men, it is not going to learn how to discern heart problems in women. Because you're right, their symptoms often look different; they're less centralized, and so on. So you can have an algorithm that works really, really well for men, but it's terrible for women, and it will cause doctors to misdiagnose, which can be life-threatening.

Casey: Now, I'm really curious about the Algorithmic Accountability Act. I actually am really unfamiliar with this, and I'd like to ask you two questions. The first is, what is the Algorithmic Accountability Act? And the second is, how [is] your work, given this act, especially important to policymakers, who should be paying attention to the work that you're doing?

Dr. Hoffman: So the reason you are not familiar with the Algorithmic Accountability Act is because that was a bill that was proposed, but did not become law, so there's nothing to be familiar with. I believe that was in 2019 and it was proposed, but it did not move forward. But it does show that legislators—Congress, in particular, in this case—are starting to pay attention to the fact that we need some oversight. And that bill was going to, among other things, instruct users of AI to pay attention to problems of bias and to correct them if they are identified. And we do have some localities, I think in New York and elsewhere, that have instructed government entities, like cities who use AI for different reasons, to try to pay attention to issues of algorithmic fairness and intervene if necessary.

But because you have the AI, which can, in fact, lead to decisions that are

wrong and really disadvantage certain populations, we need some oversight. We need to have legislators, policy makers, paying attention and trying to establish good oversight mechanisms for them.

Ashley:

One of the things I heard you talking about was the history of how we've done medical research, or research in general. So we're talking about healthcare and medicine, but I think this kind of expands beyond those spaces, from a general perspective, [of] the history of [the role of] bias. I have studied all sorts of different spaces and how someone comes to that research project, how they ask their research questions, the people that they're asking questions of— [it] all feeds into the research design and the findings that they have. And all of that history of that research then gets funneled into the algorithms, if I'm hearing some of that correctly, or at least some of that research. So the history of how we have conducted research, for example, in the medical field, predominantly focused on white men, and then our findings predominantly focus on the experiences that white men have had, creat[ing] those biases in that.

For me, one of the things that I've really been thinking about as you've been talking is how we can not only bring up these issues, around how people should be paying attention, but also how we can demystify all of the policy and politics that go into not only the things like the Algorithmic Accountability Act, but also the history of medical research. So I guess my question to you, and this is a really long-winded way of asking it, is from your perspective— these are some of the things that I've been hearing you say— but from your perspective, how do you seek to kind of demystify this area of research, especially from a policy-centric perspective, in a way that you want our listeners to understand? What would you want our listeners to be able to take away that maybe they didn't realize previously?

Dr. Hoffman:

You're absolutely right that the way you conduct the research is very, very important. And in AI, much of it is about training data. So if the training data, which is what I talked about before—if the information you use to train your algorithm is not representative of the population of interest, you're going to have problems. For example, I read an article that talked about an algorithm that is meant to help you analyze moles on the skin in order to try to determine if they are cancer or not. Well, if all of your training data comes from white people, your algorithm isn't going to know what to do when the skin is darker. And that's a huge problem, so you have to have representative training data.

There's a well-known case outside of the healthcare field where Amazon was going to use an algorithm that was going to help it decide which resumes to

pick out in order to interview candidates. Well, the resumes were from men in the training data. And so the algorithm learned that men were good candidates and women weren't, so it rejected anyone whose resume indicated that they were a woman— by name, by activities, Girl Scouts, whatever— out they went. That is very, very problematic.

In health care, there's a very famous instance where they were using an algorithm to try to determine which chronic disease patients should be referred for a very helpful program, a high-risk care management program. And here it wasn't so much training data, but it was the assumptions they made: the assumption they made was that if you had previously spent a lot of money on health care, you were pretty sick, and you should be referred to this high-risk management program that would help you. And that's what they trained the algorithm to do. Well, huge problem. A lot of African Americans don't have money, don't have health care access, so they hadn't spent a lot of money on their health care in the past. So to the algorithm, they looked like they were healthy and they didn't need this program. But of course, they needed it more than anyone else, because these communities do have a lot of chronic diseases and they don't have money to get health care, so they need the support of these programs. So that was a terrible assumption to make. And so there are instance after instance after instance of wrong assumptions, non-representative training data, and people need to realize that, as do policymakers.

Casey:

In my mind, the kind of quintessential example that I can think of [of] bad data being collected is pharmaceutical companies running trials and, rightly, they come to this and they say, “hey, we're running a randomized control trial, we want to eliminate things that could affect the outcome so that we really get a precise and a valid estimate of the effect of these drugs.” But one of the things they would do is they wouldn't include women, because women have menstrual cycles and “menstrual cycles— oh, well, I mean, those are variables and we don't want that. We want to control that out,” right? But they would walk away with just data on men, and not really understand how these pharmaceuticals could impact women differently.

So given that that's something that I would think not a lot of people know about— at least when I share it with my students, they're all kind of like, “what, why would they do that?” kind of shocked that this is true. As an expert yourself in health law, bioethics, and specifically you've written quite a bit about health information technology, how is it that you developed this expertise? How did you find— from the get-go, how [were] you able to identify reliable, meaningful information about this topic that informed the creation of your expertise?

Dr. Hoffman: So part of it was— it was very helpful to work with my husband, because we could have dinner conversations, long conversations during walks, and he taught me a whole lot. And frankly, I probably would not have gotten into this area without him. So that gave me a lot of comfort, because I had a really reliable source to make sure that I was saying things that were not nonsense.

But otherwise, I do a lot of professional reading. I read JAMA, and the New England Journal of Medicine, and Health Affairs, and all sorts of things every week. I am a big consumer of news, and this is in the news a lot. In fact, I have an article that I just saw called “‘Nobody is catching it’: Algorithms used in healthcare nationwide are rife with bias.” Couldn't be more perfect. And this is something somebody sent me, so I have good friends that know what I'm working on and send me sources. But reading is absolutely essential; keeping up on current news items and on current opinion pieces is really, really important. And having co-authors and colleagues that can bring in their expertise is also really vital.

Casey: I'm really curious because you had someone who is probably near and dear to you that could give you the background, and probably was very, very patient about explaining things—

Dr. Hoffman: Sometimes.

Casey: Well, maybe not all the time, sure. But explaining some of these technology terms and concepts that perhaps your training and your schooling hadn't prepared you for. I know, as an academic, [that] our literature can just be chock-full of jargon and technical language that is, to the outside reader, beyond understanding. So how is it— I feel like you're kind of in a special place in that you were there, and now you're an expert in this area, and you're creating research on it— so how is it that you translate this expertise that you've gained for a broader public to be able to understand?

Dr. Hoffman: I was an English major in college, so that helped me write. English also is kind of my second language; I learned it along with another language, but I did first through fourth grades in another country, in Israel. And I find that very helpful, because I essentially had to learn English in fifth grade, and it is an extremely difficult language. You know, you can spell one sound five different ways— it's horrible. But I have an awareness of that, which is helpful. And I've also gotten more into writing op-eds and pieces for a popular audience, and that has been very helpful. I have learned a lot from the editing process of those kinds of pieces. Like, who knew, but if you want a sentence to be clear, it should

be 17 words or fewer— anything more than 17 words gets long and convoluted. And so I keep that in mind. I think it's helpful to do different types of writing and get feedback on them.

Casey: How do you stay confident in your expertise, but also be willing to grow? So to listen, to learn, and just appreciate other forms of expertise that are out there?

Dr. Hoffman: All that reading I talked about is absolutely critical, and then presenting your work is also really, really useful. I'm working on another project now, and we just had a faculty workshop, a summer faculty workshop, where I presented the piece and got a lot of really helpful comments from people. So being willing to take the risk, even with pieces at an early stage that are not yet published, is really useful. Even if others tear them apart, it always makes them better. And really talking about your work. You know, it's amazing— if you go to lunch, or nowadays, if you Zoom with friends, and you mention your work, somebody will just throw out an idea that you say, “wow, this is a gem. I didn't think about [that], and this is so helpful.” So talking about it, doing your reading, being willing to present your work at any stage is all really helpful.

I have to say, a few of my pieces have grown out of questions that I got at presentations. So I presented an article and then someone asked a question, and I would answer it, and then I'd go home and think, “you know, that really would be another good whole article to write, that was a really important point that they zeroed in on.” So just being active and out there is really useful.

And Casey, let me just respond to a comment that you made about women earlier. I might get edited out— but a big problem actually is pregnant women. I don't know how pregnant women get treated for anything, because nothing is tested on them, not even eye drops, out of fear of liability. With women who are not pregnant, they are worried about fertility. They don't exclude all women, actually. I was on an institutional review board for many years. So what was done is, as long as they're not pregnant, they have to use two types of birth control— which basically is a deterrent for anyone to participate in the trial, because who wants to use two things? But they didn't straight out exclude women. Certainly menopausal women they were fine with. If you could possibly get pregnant, they wanted the two forms of birth control. So that's just a little more nuanced.

Casey: Yes. And I don't think that they exclude women much anymore, but up through the seventies, that was pretty— the preference was that you didn't [necessarily] need to have a representative number of women.

Dr. Hoffman: Yeah. I think early on, yeah. But just now it's a little more generous.

Ashley: So I actually have a question about COVID. You're an expert in bioethics and we have been living for the last eighteen months, maybe more—for a long time—in a pandemic. I know that this is slightly shifting the conversation away from what we were talking about earlier, but I feel like I can't not ask it. How did you respond to COVID, as an expert in this space? How did you decide that, as an academic who understood bioethics, understood health law, that you would then respond to the public? How did you decide to do that, and what did you do?

Dr. Hoffman: Happily, I have a media relations person at Case Western with whom I've become very, very, very close, and he started— I'm happy to talk always, about anything I know something vague about. And so he started referring the media to me, and I've been very active in the media. I think I counted [that] I have well over sixty interviews. I did do two sabbaticals at the Centers for Disease Control and Prevention, and in one of them in particular, I worked exclusively on public health emergency preparedness. So I do have a background in this area. I wrote a few articles on public health emergency preparedness as a result of my CDC work, so there is some scholarship to back it up. But I was very happy to be able to speak to the public.

I actually have here, posted on my wall, a thank-you letter from Sherrod Brown, who heard a radio interview, I guess, and was impressed. But, you know, it's a public service. It's part of what we're supposed to do as academics. If I could urge people to get vaccinated or wear masks, I was happy to do it, and I thought it was my duty to do it. And of course, once you have a few interviews, it all can be found by Google, so other people ask you. I actually was interviewed by Sputnik from Russia, by someone from Vietnam, someone from South Korea. So Google is amazing, it can lead all sorts of people to find you. But I think I do have a duty to speak to the public and try to get messages out there, [because] if you just sit in your room and write, and nobody reads it and you don't get any messages out, what's the use of that?

Casey: I'm curious— have you received pushback from folks in the medical [field], where their expertise is medicine, but they don't have really a deep understanding of technology or how algorithms are constructed?

Dr. Hoffman: I have not received pushback. I have received pushback on some of what I said about COVID from members of the public, but not from doctors. I think this message is getting out there, I think doctors are aware that there are some problems. The only issue is, you know, don't be so negative about AI that people

think it's a bad thing or that we shouldn't use it. It has to be very balanced, but nobody denies that there are these problems of fairness and bias.

Ashley: Absolutely. So I am, like, notorious for pivoting— I guess I am the interviewer who's going to pivot again today. I'm curious, broad question— the way that we categorize disciplines in academia—you know, political science, sociology, law—is quite a bit different than the way that policy makers categorize problems, by subcommittee, for example. If you could connect with any policy maker or agency to suggest policy changes based on your research and expertise, what would that be?

Dr. Hoffman: So the agencies that are relevant to the AI and healthcare work are the Department of Health and Human Services and the Food and Drug Administration, the FDA. The FDA is starting to regulate artificial intelligence; it regulates some types and not others. It has acknowledged that its traditional framework of regulation is not a good fit for AI. AI, for example, teaches itself, so it constantly evolves. So, a result that you might have had early on is going to be different from a result that you've had later, when it has learned more. And that is very challenging to regulate, so I hope that the FDA focuses more and more attention on this and that they come up with more comprehensive and sophisticated regulations.

Casey: Now within agencies, rulemaking that ultimately— I mean, it is a form of regulation, but it is still rulemaking, where it's not necessarily bound to any legislation that's been passed. So how confident are you that changes in rulemaking would be enough? Is it really necessary that we have some sort of legislative change?

Dr. Hoffman: So there are different levels. There is legislation which comes from Congress. There is regulation for that; usually you need enabling statutory authority. So for example, we have HIPAA legislation, which instructed that there be HIPAA regulations, and so the HIPAA legislation came out in 1996. In 2003, we got the HIPAA privacy rule, but that would not have been possible if there wasn't enabling legislation.

And then there's a lower level, which is— it can be guidelines, it can be rules, and that is not necessarily tied to legislation. And so it just depends. Some of the guidance is very, very useful, but it doesn't have the same authority as a statute or a regulation. And so I think we do need some regulations in this area, and regulations take some time because there has to be a notice and comment period. You have to put it out there, you have to collect comments from stakeholders and interested members of the public, you respond to them, and

then you come out with your final set of regulations. But I think that process is useful, especially with new technologies such as AI.

Ashley: I have a quick follow-up actually, Casey, sorry.

Casey: Go for it.

Ashley: And maybe we edit this out, it's up to you. From your expertise, from your area of knowledge, what would some of those regulations possibly be, that you think would be really helpful?

Dr. Hoffman: They can be about testing— to what degree do you test these algorithms? And you can require clinical trials, which you don't always have with these kinds of things, where [we] actually use them on patients and see what happens. Is there bias? Do they make correct decisions? So a lot of it is just the validation, the testing process. Who do you make responsible? The Algorithmic Accountability Act actually focused on users, if you are using, and it wasn't only in health care. If you are using these kinds of algorithms, you need to pay attention to the outcomes— to what's happening with disadvantaged populations, for example. So there's lots of different approaches that could be implemented.

Casey: Are these most useful at the federal level? Or is there room here where states could actually pass some regulations that could at least start to— or maybe experiment with different types of regulations that might work best?

Dr. Hoffman: Often it is easier at the local level, and as I said, there are some localities that have a few rules floating around. The problem with AI is it's often used by people in more than one state. So we have these large health systems, where Cleveland Clinic has operations here in Cleveland, but also in Florida, and Saudi Arabia, and wherever Mayo Clinic is in Arizona and Minnesota, and so on. And so, what do you do if you have state-by-state regulations? So you have an algorithm and you have to have people remember [that] you can use it in Minnesota but not in Arizona, and patients move around, and it just gets very difficult. So sometimes it just makes sense to have rules at the federal level.

Casey: Yeah, absolutely. Now I've got, I guess, is it a pivot? I don't know, it's our final question, so I guess it could be a pivot. I'm curious, as an academic doing research that has some pretty serious applied implications, do you see the work that you're doing, and the work that you're doing on sharing this research, as part of your civic identity?

Dr. Hoffman: Yeah, absolutely. I think— I get paid to do research and writing, and I think it

should be of benefit to people. Otherwise, it's a waste of money. And that is sort of the contribution I make, aside from teaching, is I hopefully develop knowledge. I very much hope that policymakers see it and find it illuminating and useful, and maybe once in a long while I sway some opinions. Other people do a lot of really good things, I focus on research and writing, and I hope that is my civic contribution.

Ashley: That's fantastic. Thank you so much for being on the show with us. We really appreciate it.

Dr. Hoffman: My pleasure. It was a great interview.

Casey: Thanks for coming on. Bye.

Casey: Thanks for listening to the Growing Democracy Podcast. I'm Casey Boyd-Swan, and with me, as always, is my co-host, Ashley Nickels. Our podcast is edited by Gheramy Demery at Golden Ox Studio, right here in Cleveland, Ohio. This series is supported by the Northeast Ohio chapter of Scholars Strategy Network. If you like our show and want to know more, check out our website, growingdemocracyOH.org. If you want to support the podcast, as well as get access to behind-the-scenes content, live chat, and swag, featuring designs by Donuts and Coffee, head over to patreon.com/growingdemocracyOH. Join us next time when we continue this conversation about demystifying policy-relevant research.