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**Briana Lopez-Patino**

00:45

All right. Welcome everyone to our webinar, rebuilding trust and science, a friendly reminder that attendees are not audible or visible, but you may ask questions through the Q. & A function in Zoom.

Also, this session is being recorded and will be available on the Hastings Center website later in the day for viewing with closed captioning.

This is a special event based on the just finished special report published by the Hastings Center. I'd like to welcome Doctor Vardy Bravitsky, who is the President and CEO of the Hastings Center.

**Vardit Ravitsky**

01:27

Thank you so much, Brianna, and thank you all for joining

Trust is one of the timeless concepts that we could be addressing today as we emerge from the pandemic that showed us how critically important it is. And as we're entering the era of AI in health, recognizing how once again trust will be key to ensuring, we're able to read the benefits AI has to offer.

So this special report that we will be discussing today showcases the role the Hastings Center plays in recognizing critical issues, in partnering and convening, in producing top shelf scholarly contributions, but also in taking the last step of making these contributions accessible to decision makers and to the general public, which is what we're doing here today. So I'd like to thank the editors Lauren Taylor, Greg, Kevin, and Millie Solomon for the work in putting together such a comprehensive look at this critical issue. and I'd like to introduce Lauren, who will be facilitating today's event. Dr. Taylor is an assistant professor in the Department of Population Health at Nyu, with a joint appointment in the division division of medical ethics. Lauren, I'm really looking forward to today's discussion. Thank you all.

**Lauren Taylor**

02:45

Thank you so much, Vardit. It's so fun to be here. I just can't tell you all. Well, I will tell you all how long this has been coming.

We started this over, I think, 18 months ago. and I've been joking with the authorship team That that means that it took us twice the time that I took to incubate a whole human life to incubate this special issue. So it's really fun to see so many of you on the line and get to share a flavor of what has gone into this work.So let me just offer maybe 2 or 3 kind of framing comments about the special report itself, and then also how we're gonna try and broker conversation today.

The special report really came about partly through a joint effort between the Abim F foundation. That's the American Board of Internal Medicine Foundation and the Hastings Center, who share an interest in trust and trustworthiness. and then was also supported by the Hastings center and the goal was really to lend some conceptual clarity or to bring some conceptual clarity to a field that is notoriously complex uses overlapping terms, uses terms that are differently defined by different authors, you know. Trust to philosophers tends to mean something incredibly specific and narrow, and yet the way that we might use trust as a piece of speech at our dinner table, or in conversations with friends. can be really varied.

And so there's a huge disconnect between the empirical literature on trust which, as we know and health services research, the empirical literature tends to move fast cause that's what gets funded. So there's a lot of empirical work that has really varied definitions of trust. And then you've got this like philosophy, and to some extent a bioethics literature on trust that wants to really carve out a narrow definition, workable definition, and a highly internally valid definition of trust.

And so you face a real challenge when you go to literature and try and say, like, Okay, we're coming out of a pandemic.

We think we have something of a trust crisis on our hands. We wanna build trust. What does literature have to offer by way of instructive guidance?

And the answer was like, Not that much. And I really came to understand that first hand when I was doing a review for Mail Bank, Quarterly called 50 Years of Trust

and on the heels of doing that review, you know, I came to Hastings and I said, Look, I think there's really an opportunity here to do some conceptual work for

health policy health services research to some extent bioethics in line groundwork about how we should think about trust and trustworthiness, and what some of the guardrails might be as we try and build

these goods going forward. So that was the impetus and spirit in which we began the special report.

We came to have this fabulous authorship. I believe there's 15 essays in the final report. You will hear from 5 of the authors today. And

and you know I will say we were intentional about having a very disciplinarily diverse group and having a mix of methodological approaches that carries with it all sorts of benefits like there's something for everyone in the report. If you're a social scientist you'll find Social science pieces. If you are more of kind of a conceptual theorist, you'll find those kinds of pieces as well if you like p-values. There's a whole set of things there for you as well.

but in doing that it comes with challenges, you know. I think we got to the end, and as successful as I think the report is, do I think that it has produced, like a single unifying definition and conception of trust that we can just go forth with.

No, I don't. And do I wish I did. We did part of me does. And so I'm both like deeply interested and invested in exploring the differences that remain, because I think we did come to at least like significant convergence among the authors on what the key elements of trust and trustworthiness is.

* But it's not as if we're. This is a consensus statement, right? There is still internal kind of disagreement or diversity of thought, and part of that is what we'll hear from some of our authors today.
* So with that maybe you know, I should at least just say aloud who the folks are on the line here, and I won't give the formal essay titles, because, as each one speaks I'm gonna drop the link to their essay in the chat, but with us we have 5 authors. We have Dr. Michelle Chou, who's from my home institution, Nyu Grossman, School of Medicine Art. Kaplan is also a mentor of mine at Nyu Gross and school of medicine.
* and then we have Dr. Leah Rand, who's up at
* Harvard, Mass. General Brigham. Whatever combination of word salad we're doing for all the Cambridge institutions at the moment we have Dr. Melissa Creery, who's from University of Michigan School of Public Health, and we have Deirdre Mylott, who's from Pres. Gamy.
* So the first question I'm going to put to my friends and colleagues who were the essay writers, is just.
* Forget what you would say if you were going to a conference, and you're presenting your essay. Tell me, and tell the group who's with us.
* what you, how you would describe your essay to the Uber driver who's taking you to the airport like layman's terms in a minute or 2. What's the gist
* and I'm gonna ask this question to each of you. I put the order in the chat. So maybe we'll go, Leah, Michelle, Melissa, Art Deirdre. And just as a reminder the follow up is going to be.
* what questions do you have from for one another. So with that, maybe I'll turn to you, Leah.
* 

**Leah Rand**

08:39

Yeah, thank you, Lauren, and and thank you for this introduction to trust because trust is important, and my Uber driver, and actually end up having these conversations more often than not on my way to the airport.

* It's really important that we trust our public health agencies, and one of those is the Food and Drug Administration, the FDA. And the reason why it's important to trust their decision making is that they're approving the vaccines that we take ourselves, and that we're hoping everyone else takes around us so that we're not transmitting diseases. And this was really called into question. If you cast your mind back to August 2020,
* there were political statements. We had appointees and elected officials making statements like, we'll have a vaccine by October, or we're gonna have a vaccine really soon. And
* people started to get worried. What was the FDA going to be doing? Were they rushing through something? Were they holding to their usual approval standards that we all rely on to know that our food and medicines or our medicines are safe and effective, and we wanted to explore. You know, when the FDA is taking actions that are so politically relevant and have political interests, what should it be doing
* to show that it is still a to be a trustworthy agency, and to show the public that it's acting in trustworthy ways, so there can be a lot of interests riding in its decisions. And yet
* we have a lot of personal and public interest in making sure that it's trustworthy and making decisions that are right about what's safe in effect or right for us about what is safe and effective. So in our our paper, we outline 5 conditions
* that we believe it should be meeting, and these we set up, so that in the next pandemic, or in the next moment of emergency or political turmoil. Around one of their decisions. There's some guidance and some sense of saying, we're holding ourselves to these standards for approvals.
* 

**Lauren Taylor**

10:47

Thanks so much, Leah. We'll go to Michelle next.

* 

**Michelle Chau**

10:51

So if I were talking to an Uber driver I would start off

* just telling him how we wrote an essay. My colleagues at Nyu, and we wrote it with 3 members of the leadership at community organizations. That we partner with in our work at Nyu. And these are nonprofit organizations that provide educational social services
* to minoritize communities in New York City, including black Latinx, Asian, and immigrant communities. So these were all our authors. And in our essay we really describe how community based organizations serve as trusted messengers
* to community members in different health contacts, and that they often deliver health information. They endorse health information from institutions, from government. They make referrals to health organizations, and we really describe how this happens and how trust flows throughout this process. We discuss why trusted messengers are needed.
* you know, because of
* people's past, because of the reputations of these institutions in communities because of individuals, past negative experiences with institutions, with physicians.
* with clinicians because of political contacts. We describe
* why community based organizations are really well suited for this role because they're embedded within their communities, their organizations that understand their cultures, their languages. They know strategies for engaging with communities. They work with these communities.
* and we also talk about in the essay. You know how they service trusted messengers, and how this is accomplished.
* 

**Unknown Speaker**

12:33

and we go through a couple of different ways that this happens.

* 

**Michelle Chau**

12:38

so we also talk about how, in order for CB. O's to serve as trusted messengers. There's also sort of these, like 2 layers of trusted relationships that are needed. There's trust between the CB. O's and local healthcare institutions or academic healthcare systems. And there's also trust between

* the community based organizations. And it's community members that are needed. And there's just trust building throughout both of these processes. So
* there's healthcare institutions that are working with Cbos to build trust.
* There's community members and Cbo S that are working together. Cbo, serve these community members and then in the essay. We also go on to describe examples of programs from the Cbos that are authored.
* in the essay. So, and we talk about how they leverage trusted relationships as well. So with Arthur Ash Institute, we talk about the barbershop talk with Brothers. Which is an HIV prevention program where they work with barbers who are trusted in communities. To provide health information. They train them.
* we discuss, make the road New York where they train community members to become peer educators and community health workers in healthcare settings.
* And with India home, where they run senior citizens, centers and they also leverage trust through faith based leaders that they work with and working with other trusted cbo. So there's just trust. Throw it, or trust, or trust sort of like, flowing throughout this entire process.
* And then we also just talk about kind of the at the end. We talk about how we learned several lessons. From these programs, how they engage community members.
* they build partnerships through other communities. They utilize
* just culturally competent services. And and they're huge advocates for communities.
* so that's sort of a sum of the article
* 

**Lauren Taylor**

14:34

perfect enough to wet the palette. Thanks, Michelle. Melissa, I'm coming to you next.

* 

**Melissa Creary**

14:40

Yeah, thank you so much.

* so I am a very quiet uber passenger. But if I were to be discussing this with my uber driver, it would start out by saying, You know, I guess it's really great opportunity to write an essay with a colleague, Dr. Beneto, and we were trying to discuss
* the performativity of trust, and he might say, or she might say.
* Well, what's the perform activity mean? Right? And so I I'd engage in conversation about like
* performance exactly what it looks like in terms of having folks kind of play with service.
* Give us a show of what they think we want to hear when it comes to these narratives around trust, particularly in these academic and scientific spaces.
* And the ways that
* it really does damage for the community in which they're trying to engage with to collect
* good and meaningful data. And you can't collect good and meaningful data without that trust being very present. So we talk about
* the damage that gets done when trust is seen as a performance.
* And we talk about particularly the damage that's done to historically marginalize and minority community members.
* and the ways in which how this performance takes place is based in value.
* and how often the values of those in the healthcare system and other systems are misaligned with the values of those in the community.
* And so we take a look at this kind of idea of performance through
* how we think about research, inclusion, initiatives.
* This. These attempts, for you know, research and academic spaces to be patient centric without this kind of really deep and realistic look, and then open conversation about social capital and power.
* about how we're inviting people to a table without really interrogating what it means to come to this table, and where you've kind of broad socioeconomic socio historical factors.
* That make them so enticing to be invited to the table to begin with.
* and we really are attempting to to talk about
* how the only way we can get to the space
* beyond performance and into this area that it's, you know, restorative for communities is when we take the time to really
* sit with, be embedded with and listen to communities about how deep
* you know, whatever that research, question or intervention has to go. So you know, we're trying to bring to light
* that this value misalignment can only
* correct itself
* when we start to have these open conversations about how hard trust building really is.
* and the time that it realistically takes to build that trust.
* and then to understand, when we do these kind of superficial action that the community understands
* and sees them as superficial and how we can move, you know, have a discussion about how we can move past.
* pass that perform activity into the space where we're doing really deeply embedded engage community work that takes the time that we're often we often don't have. So it's a much larger structural issue. That we're trying to get at. And unfortunately,
* All the interventions are, are, most of the interventions are service level.
* 

**Lauren Taylor**

18:41

Thanks, Melissa. I have commended your essay in particular to so many folks, because I often have an inbox in inbox full of people who are

* like realizing a new, how important trust is. And you can't fault them like it's a managerial instinct to say, kind of I want a quick win like, I want to show the community
* quote unquote. How serious I am about this like, what can I do tomorrow?
* It's just you and I went back and forth on this like in the line edits, I think about your guys's essay is like, is there such thing as a quick win in building trust?
* And I think your response ultimately was, no.
* we can come back to it. Okay, I'm gonna come to art next. And then, Deirdre, you're gonna round us out.
* 

**Arthur Caplan**

19:27

Hi! So thanks, Hastings for doing this. Thanks, Lauren and Greg for working on this special issue very timely.

* So I got interested in this because trust
* in science, however defined. But people are polling about it whatever they mean. But the polls show big declines in trust in science over the past few years, mainly fuelled by Covid, I think. But other factors may be involved.
* I'm gonna say, I think, what they mean in the surveys of trusting in science, and scientists
* respect for their expertise.
* Acceptance of their pronouncements is worthy of attention and objectivity that they're not trying to grind the particular acts when they speak as a scientist. And I'm sure there's 9 more values that we could introduce. But I think that's what the
* polling kind of thing is up to. So why is this slippage going on? I'm not sure anybody is fully
* explained why science is falling in the polling and medicine, too. By the way, not nursing is much interesting enough. And people still say they like their doctor, even though they don't trust doctors as much.
* There are disinformation attacks that are organized. We have a Presidential candidate running on a I think I'm gonna suspend research on infectious disease for a while. Platform Rfk. Junior. Among other things.
* disappointment with experts, pronouncements during covid people say they wavered or they flip flopped, or they weren't clear.
* Failure to engage at the grass roots level where science communicators tend to be is on national outlets. not at the local school board, or church or mosque, or
* Kiwanis Club. I don't think
* those audiences are getting much in the way of scientists, but they're hearing a lot from people who claim to have information worth listening to.
* and I have to say, and I'll irritate Lauren with this, but she can come back and argue with me some more fundamentalist parts of religion see science as an enemy.
* The this goes in and out from Charles Darwin to today. I'm talking more about the evangelical end than I am. What's going on at the Universalist or reform Judaism experiences. But there is this notion that science is positing truths and beliefs that
* people who are literalists about the Bible may not accept. And so that's got a lot of preaching going on about views of science that are, II would say, attempts to undermine
* science as the authority as opposed to religious authority. Again, in part
* of a religious outlooks? Not by no means all. So why is the public susceptible to these attacks, if you will. whichever direction they're coming from?
* And I think it's because the public doesn't understand science. It doesn't know, as I tried to explain in my essay what it is. Interestingly enough, I didn't say this quite as much in my essay. I'm not sure scientists know how to explain what science is, and I'm definitely sure talking to my doctor friends
* around the country. They have no idea what to say that makes medicine, a science, I mean none. So you'll get answers like, well, it's about what appears in New England Journal of Medicine, or it's definitely something that is evidence based.
* and then you sort of push a little hard and say, well, what evidence like
* random, clinical, randomized clinical trials? Testimonials! Historical inheritance of tradition, and things fall apart fast.
* So my essay in part is an attempt to explain this issue, and I think my roots and I'm not an ethics. But as a philosopher of science definitely have me oriented toward thinking. One
* problem of trust
* with respect to scientific and medical experts
* is epistemological, that is to say. We don't know why it is that something should be valued because scientists say it
* where scientists publish it.
* So the first thing that people don't get is that science is supposed to be fallible.
* When you hear somebody say, Well, you changed your mind, or you're not giving the same message that came up a lot in Covid is the virus strain evolved?
* That's considered to be a weakness by many people. If it's true, it ought to be true
* for all time, not for 3 weeks, but at the same time new evidence, new information experiments that fail, as Carl Popper argued decades ago, falsification is one of the key
* striving attributes of science. So saying that what we say could always be wrong, for what we say could in theory be disproved is not a sin. It's a virtue of science as opposed to religion, which may sometimes say what we say is true, and there is no way to counter. There's no way to falsify it. It's clear from authority of our holy book.
* Second, disagreements do not make something not worthy of being called science. We're supposed to try and push and prod and challenge people's beliefs and the adequacy of their warranted evidence for those beliefs. But disagreement is something that
* people who want to attacks on. It's harp on right away and say, Oh, well, look! The experts don't agree, so there's no reason to listen to them. They're all over the place.
* I'm not even sure they are all over the place most of the time. There may be a minority who have a position to hold out, and the majority don't. But again, disagreement is misinterpreted to mean you don't know what you're talking about.
* Scientists are willing to admit errors. Other outlooks in life, whether it's
* art. Criticism or spiritual belief may be less willing to say, I made a mistake. I have an error.
* But again admitting error puts you at a disadvantage when someone attacking you says
* I have. I may not know anything about viruses, but I'm an authority. I'm here to say I've succeeded in business, and I've looked at all the evidence, and I've talked to Joe Rogan on his webcast, and I'm ready to say this is true.
* Celebrities. Do. Did that a lot during Covid saying, you know, vaccines are harmful. And it was sort of like.
* where's that coming from?
* Science has another interesting aspect that people forget. It maintains a graveyard of bad and undermined ideas. That's what makes something science. You sort of look back and say, Oh, never mind, no, ether oops. Nope, your ulcers are not caused by stress. Actually, bacteria. Sorry we were wrong, and that is exactly the kind of thing you wanna trot forward attention to history.
* showing how progress is made with respect to dumping bad ideas and acknowledging that they were bad and wrong. So those are all attributes, I think failability, falsification.
* You don't understand what science is. Then, when someone points out that you've got an error, you got a disagreement, or you admit that you had an incorrect position. Well, that sounds like then I shouldn't trust what you say, cause you don't know what you're talking about
* the big area. I think that distinguishes science which scientists forget about themselves
* is that science is practical.
* it really gets measured in its ability to intervene in the world and obtain ends that people desire. So if I want to get to the moon, I do follow physics, and my physics is wrong. If I consistently can't reach my goal. If I say, I have a theory of disease, say
* bad miasmas, that is to say, polluted air that's causing disease. And, in fact, there are plenty of people getting the disease where there's no polluted air.
* then my theory is that right? Or, to put it another way. medicine is proven at the morgue. You say you know how to cure things. You say how to fix things. but if they're dead bodies stacking up, then you don't know what you're talking about.
* That practical side sometimes gets lost gets lost
* because scientists tend to be enamored with physics and chemistry as the underlying and molecular biology as the underlying truths neglecting the practical end of science, agriculture, engineering, medicine, veterinary science. Those aren't necessarily the
* sciences that are used to illustrate what makes the whole enterprise. Science, the practical. in my opinion, is very, very definitive, and needs to be explained to the public
* when they're up against disinformers or people were just out to attack science. Just 2 more points, and then I'll shut up. I think science can be communicated. I'm in the Albert Einstein camp with a few can explain it simply. Then you don't understand it, anyway.
* but I think what's happened in the Science community is it's done a horrible job of being able to talk to the public or the Uber driver, or anybody outside the community of the science you're in about what the hell is going on, so nobody's trained to do it.
* More importantly, no one's rewarded for doing it.
* We've had a phenomena that dates from Carl Sagan, the astronomer who used to show up on Johnny Carson and other media outlets to explain astronomy and astrophysics.
* But he was never elected to the National Academy of Sciences. His colleagues basically consulted him for trying to be a public figure in science.
* If you think about Covid amass world wide events, you probably can't get past 5 people on one hand, or you could think of as spokespersons for science.
* you could easily get up to maybe 50 who were disinformers about science, and we're all over the place.
* So communicate. So, knowing what science is like, that becomes very, very important, then, being able to communicate about it becomes very, very important. But we have to start to reward and acknowledge that that is something that scientists were good at it should do, and that is a duty owed back to the public who pays for much of the science that they should take on that task, and I think they failed
* during Covid, for sure. And that's part of the reason for the decline. I think, in trust in science.
* 

**Lauren Taylor**

31:03

Thanks, art. as many of you on the line will know. Art writes about many things, but it was fun to watch and do an essay on Philosophy of Science, which I believe is like his first love. So

* Deirdre, I'm coming to you to round us out
* 

**Deirdre Mylod**

31:17

sure. So when I when I get into an Uber often, I'm going to an airport, and people say, What do you do for a living? And I see. Have you ever gotten a survey after you went to the doctor went to the hospital once Department and although Prescene does a lot of other things related healthcare quality. That's what we're most well known for.

* So the paper is about what patient surveys can tell us about what patients talk about with regard to trust
* and how clinician behaviors might influence stress. Although I'm I've been very influenced by Dr. Cleary's grace article, because I'm really struggling with the performative versus authenticity. Nature. But what Rsa does is it looks at first what 2 patients say about trust in the comments and the things that we find, you know, really high levels. First of all, that if patients talk about trust, it's almost always a positive thing. 92% of the time they're saying something positive. So trust is both
* desirable and a good thing. And it's also something that is being experienced. Often
* and then of the comments when people talk about trust more than half the time they're talking about trust, and immediately talking about their willingness to recommend. So they really tie together, at least in the narrative that they provide in a patient comment. They tied together. I really trusted my doctor. I would recommend her, or what you did, make me not trust you. I would never recommend you to other people that more than half the time those concepts Co.
* 

**Unknown Speaker**

32:41

Occur in the same phrase or the same insight.

* 

**Deirdre Mylod**

32:45

and then of the the comments where they're not just specifically talking about recommendation. Then most of those comments are specifically about caregiver behaviors. So the who that they trust is very important in what they want to talk about. And when we group the concepts. What is it about their care provider, their clinician? Others practitioner. What they're talking about must often is courtesy and respect. Their skill and knowledge.

* and then explanations, listening and reliability. And others have talked about Lauren. You you talked about in the intro that confidence is necessary, but not sufficient. Certainly skill. Knowledge is one of the more common topics, but courtesy and respect comes up even more often. And we have a little bit of a sidebar in the essay. That's just a fun finding that. What we see is when people, when they talk about courtesy and respect and also experience, humor that can enhance trust.
* But if they experience a lack of respect, less humor, that can really reduce trust. So you have to know, really know your audience and know when it's appropriate to create the intimacy that humor can attempt to create.
* But we also look at not just what people say on surveys? How do they evaluate what you know? What score or grades do they give to different behaviors? And then how do those relate to their intention to recommend, which we use as a proxy for trust. It's not exactly the same thing, but we know that it co occurs very frequently. And what we find then with, you know, the hard data is that the things that are most likely to predict
* intention to recommend, and therefore I trust you enough to trust you for someone else is confidence in their care provider. So that confidence being necessary but not sufficient.
* Staff working together, which we see as sort of together, you will keep me from being vulnerable. It's I'm not. I don't have to trust one or the other, but all of you together will keep me from being vulnerable in this scenario. And then the third comment, or the third topic that comes up in those our data analysis or communication and empathy. So the interpersonal relationships? So we look at the comments we look at the key drivers. And the last thing that we talked about was that friction, the things that are not as important
* wait times and accessibility and process things frictions. They're not the most important things for trust, but they absolutely can erode trust. And the more friction that people experience, the less likely they would be to recommend an encounter. Because that trust has been eroded. So that's how I would talk about it to an uber driver.
* 

**Lauren Taylor**

35:05

Oh, great Deirdre! And I just want to call out, lest you think that the writing is not just delightful in this special report? Deirdre and her colleagues have this great line on the humor point in our analysis. Humor.

* I'm gonna butcher it. But humor is a condiment as a condiment, not a main course. Yeah, I just love that one.
* I should also just call out your Saturday for those in the audience who might be kind of into sort of nerdy, quantitative methods.
* Deirdre and her team uses like fascinating natural language processing approach on giant giant reserves of proprietary data that only press gain he has access to. So it's really a very
* cool and special and fairly unique window into how patients deploy this term in their own narratives of their experience. Great, I just want to continue to encourage. We already have a whole bunch of questions kind of coming through the QA.
* But I am monitoring them, and I am trying to respond to those that are easy to do. Just know if you're on the line, you wanna ask questions. Someone is actually eyeballing this, and we will get to QA. You won't just be questioning typing questions into a void.
* I'm gonna turn now just to a couple of follow ups amongst the panelists. So I think, Melissa. Maybe you had a question. We'll start there and then I'll come to you, Leah and Michelle.
* 

**Melissa Creary**

36:28

Yeah, thank you. And thanks all of you for giving really great breakdowns of your paper for us.

* My follow up. Leah is, I'm I'm thinking about the FDA a lot right now. Friday. Tomorrow. FDA releases
* a decision about Crispr. And what's going to happen for sickle cell populations. And I'm deeply invested. And those conversations.
* and with my public health hat on and my former career at the Cdc. I'm also thinking about these public health agencies
* that you know. Take on. I'm thinking about what Cdc. Like those public health essential services, right? And
* after Covid, those essential services
* got? You know, a revamping with equity dead in the center of that model of how we're thinking about what gets delivered and how we're thinking about public health.
* In general. And I definitely think Covid has changed all of that. And you're bringing to light that Covid should be changing the way we think about this, especially as agencies are trying to
* 

**Unknown Speaker**

37:39

pivot and respond

* 

**Melissa Creary**

37:41

and so with these 2 things in mind. This idea of you know how Sda is going to be releasing something that has a lot of questions around.

* you know. Neglect for for a response to a, to to historical neglect, for population like difficult disease, and thinking about how equity is being so kind of meaningfully
* and intentionally inserted in spaces. How do you envision? Equity as part of the framework that you're providing for the FDA as they move forward.
* as you suggest, within or beyond the 5 suggestions that you have provided for us.
* 

**Leah Rand**

38:22

Thank you. That's that's a really good question. And certainly

* equity.
* II don't want to be performative in saying this, that it's important within our organizations and institutions. And as a consideration. and you know, the FDA in something like
* vaccine approvals or this decision they're making tomorrow And in our framework we haven't explicitly addressed it, and I certainly see it in actions. They're taking around clinical trial diversity, and trying to understand. Is there evidence sufficient to address a diverse population who will be the users of the medicines that they approve
* and II think it's important, too, that their mission is different from the Cdc and so it's been kind of central to
* our view our conception of the FDA and why we think trustworthiness is predicated on its review process. And the integrity of that process is that they're making what we hope our scientific decisions with some value in informed about you know. How uncertain can our evidence be? How great is the medical need that we're willing to accept more uncertainty, and that can make equity
* look really challenging when there is a large unmet need. But the answer isn't to approve something that isn't gonna actually meet it
* and to create either like false hope or potential for harm.
* And that's where I think the conversations and being connected to the public.
* Whether we we talk about connection to public preference when you're making a public health decision
* versus for the sickle cell case. You mentioned how important, then it is that you have connection to that patient population to understand their specific concerns, and where
* like, they're willing to accept uncertainty.
* Thanks, Leah. Leah, you actually had one right back at, I think Michelle and Melissa so do you want to fire away? That's true. Thank you. So II read Melissa's paper and was really struck by the concept of bounded justice. I was telling her I just brought that up to a colleague earlier today who had a concern and
* it also left me. And and what you were telling us about is this kind of worried about what to do next like how to sit with and really engage a community. And then, Michele, with your paper and working with these community based organizations. II was just hoping to hear a little bit in conversation, of
* how how we do that work. That sounds so challenging.
* of learning about and responding to an injustice in a non performative way. And Michelle, that has come up in your work list. If Michelle's model is maybe what might be one step towards that.
* 

**Melissa Creary**

41:27

Yeah, I really appreciate that question. Thank you. Because I

* I think one of the responses to how we get beyond performativity is to actually engage with community based organizations who, as Michelle has pointed out our trust messengers. So how do we then use kind of the cbo that's a conduit such that via alignment of values that sits with the Cpos, and who they represent.
* begins to get worked out with, you know, an alignment, hopefully or realignment, or readjustment. From these structural spaces in the healthcare system, and so I'll yield the floor to Michelle, to, you know, to to enter that conversation. But I
* it's exactly what you're positing is that we? We have to depend on the trusted messengers to help break down and give us the space to create the meaningful trust that we're looking for for the data.
* 

**Michelle Chau**

42:28

Yeah. So I could speak to that a little bit. And II think Melissa's essay also kind of called out, Cbpr is sort of the action. To kind of create, build trust. And you know, I think, our section at Nyu.

* you know, most of our projects are community based participatory research. So you know, we're all, all of our projects are you know, we're we're working on research projects with community organizations, you know, and I think I mentioned this in my essay to you know we fund them to be part of our projects. They're constantly a part of all the conversations we have
* in in our project meetings. We have, like, you know, Bi, weekly meetings with them, just discussing all the research instruments that we create getting their feedback on what community members think about
* what their concerns are. You know, we're we're developing a proposal right now, and trying to understand, like you know, what sort of interventions they need. so. But it's but it's a continual process, and you know II appreciate it, Melissa. There was a quote in Melissa's article also about how
* you know. We do. We do value Cbpr. In one respect, but we don't get as much funding, and maybe more funding is needed, because, you know, having come from a non Cbpr. Background and then moving to Nyu, I absolutely see the difference in how much, how many resources are really needed for Cbpr. And how
* you know, I feel like we need more funding in this part just because, like you have to, you have to work with community health workers, you have to work with. The community based organizations. And that the work is just you. It just has to sort of continue. But you know, even that is not enough.
* because, you know, I've we've walked into.
* you know, research focus groups where we worked with community based organizations to kind of recruit people.
* And I've had people walk out as soon as they hear that we're from Nyu and that it's research. So it's it's not enough. You know, we're working with community based organizations. The community based organizations are working with these people in the community. But there's still that kind of like lack of trust. That needs to get overcome somehow. And you know, we're continuing to work on that. But
* yeah, I guess I guess more needs to be done.
* 

**Lauren Taylor**

44:56

If I could just jump in on that Michelle cause I just wanna highlight both your essay with

* Nadia Islam and your colleagues. And there's another essay in the set that's about a different kind of community based organizations, artists. By Jill Sankian Patrick Smith.
* That is also excellent about
* the sometimes uneasy, certainly potentially valuable, but potentially tenuous as well. Relationship between artists and public health systems and health systems. And I wondered if you would just say word more, Michelle, about this risk, that
* if Cbos are trusted in the community and healthcare is not particularly trusting the community by virtue of linking those 2 up best case scenario. Cbos. Lend the health care
* institutions some degree of trust, and it buys them time to do some authentic trust building themselves.
* Worst case scenario is that it bleeds the other direction and healthcare which is untrusted now has robbed the community based organization of whatever trust was previously there.
* And I just wonder if you have any experience like seeing that actually happen empirically, or if it's a concern for you guys in your work that you wanna both be close to the cbo, but not so close to the cbo that you
* kind of defile them in the eyes of the community that you're trying to engage with
* 

**Michelle Chau**

46:16

right? And I think you had asked this question sort of throughout the process. As we were writing the essay, and II asked some of the I was the other authors about this as well, and they didn't say they necessarily saw that. So I don't know that we have any specific examples of that happening. But I also think it's just because the organizations that we work with.

* you know, are very well known in their communities, and they offer so many different services.
* And I don't know. Maybe that happens. You know, every once in a while, like, for example, it could have happened when you know those people walked out because, you know, they didn't realize a research study was going to be happening that type of thing. But
* yeah, I don't know that I have a better perspective on that.
* 

**Lauren Taylor**

47:03

A Michelle. Did you have something you wanted to put to art.

* 

**Michelle Chau**

47:07

I did.

* So are I really appreciated your essay and sort of the practical advice you have. For you know scientists talking to committee members. I was wondering if you have any kind of perspective on
* how sort of like political affiliations have kind of
* taken on a role in this sort of communication of
* science. And just sort of explaining sort of how that has happened. Cause. I was just sort of thinking about. You know I was at a health fair a couple of weeks ago.
* giving out materials for Covid vaccinations and trying to explain sort of the value of science, and you know what? What makes it credible to somebody who didn't really believe it, and
* he sort of brought up his political affiliation and and didn't see. Seem to, like, you know, be interested in sort of the arguments about science, and you know how the vaccines were made. Things like that. So I don't know if that was addressed in your essay. But
* 

**Arthur Caplan**

48:10

oh, it wasn't. But you know, I think it's pretty clear that a lot of Republican or conservative politicians think of academia as left wing

* full of the Liberals. You can see it in the State of Florida as they try to reform their State University system. And there are many other private schools that are saying, you know, we're gonna clear out. This leftist
* bias in many of the departments, as scientists usually don't think of themselves as political at all in their professional roles.
* and a lot of them, in fact, political in any role. But you know they just sort of come up with evidence and publish it and move on to the next study. But I think the scientific community has not been
* very good about recognizing the politicization that has taken place. It's really of academia, and that's where most of the scientists and the doctors live or industry. And that's where most of the conflict of interest
* charges live for scientists and doctors who work out of their.
* So I think we have to explain why it is that science can be trusted to be objective, no matter what it's.
* Context, environment, or origins are that the methods that the peer review, that the willingness to subject the views to critique.
* really help ensure objectivity. But I do think
* we've got a big phenomena of right left.
* the right being more aligned with religion, the left being more aligned with science. And then you've got
* related to that a deep strain in American culture which we're never going to solve today. But it's anti-expert.
* I don't need experts. I can handle things on my own, the rise of autonomy and covid. I'm gonna decide what's best for me. I don't need to listen to anybody about anything.
* That's a very powerful value. That's not
* bred by Covid. It's been around. It's the frontier mentality. I don't need experts
* 

**Lauren Taylor**

50:33

team. We're already at about 1 53. So I'm gonna lift up a couple of the panelists questions. And then I'm gonna close with asking each of you like. What's one thought that you either wanna underscore from your essay, or I thought you've had since you did your essay.

* Because, you know, we? We turn these things in, and they were done and dusted
* a while ago. So
* new thoughts are welcome as well, Deirdre, I want to come to you? Someone asked on the QA.
* And I think it's a great question if, as you say, we generally conceptualize perceptions of trust as resting on adjudications both of a physician's competence and the something else which you, I think, called courtesy and respect.
* What do you have to say about?
* Are patients in a good position to judge physician confidence. And like that's a question I'm sure, that shot through Prescene's work well beyond
* trust. But how do you think about that?
* 

**Deirdre Mylod**

51:28

Yeah, it's a great question. And so certainly, first of all, the the surveys are people's perceptions, right? And and we're not all experts to arts point but perceptions are often very directionally correct, and I'll give a an anecdotal example. There used to be an inpatient survey question that asked skill of the physician which wasn't even just confidence, and that I have a reason to come. But I'm assessing your skill.

* It was not a popular question among physicians to see that for this exact reason, and at the time when that was on the the inpatient survey, we had actually correlated inpatient data with physician engagement data, and the physician surveys asked them the quality of the medical staff of this organization.
* and one of the strongest correlations between what patients thought about their hospitals and what physicians thought about their work. Environment was the correlation between how patients assess the skill of the physician, and what doctor saw the quality of medical staff.
* So it's it is not so. We have to both say it is subjective. It is whether or not, I think you're competent, and whether or not you're performing or demonstrating authentically competence. So it's not perfect. But it is sure related to a lot of other things that would Devtel, and say that there's something important there. And the last thing I would say to that is
* it should never be used as a defining grade of a physician's competence or skill. But it is a really big part of whether or not patients feel like they're getting their needs met. Whether or not they feel safe, and whether or not they trust you.
* 

**Lauren Taylor**

52:58

Awesome.

* Leah, maybe I'll come back to you, and someone's pressing on something that I think we went round and round on in edits on your essays. Can you say something about the difference in your mind between the legitimacy of the FDA and the trustworthiness of the FDA. Is there daylight between those concepts? And if so, how do you think about it?
* 

**Leah Rand**

53:18

There can be. So I think one of the challenges that remains is this the variety of definitions, and that comes both from different disciplines. And, as you pointed out, trying to find a good definition of what does it mean to trust, or what is trustworthiness? And so one distinction we could make is legitimacy as in political legitimacy. So

* like an elected official, has political legitimacy of that office and has a certain type of legitimacy that's different from then acting in trustworthy ways, and, you know, fulfilling voters, expectations of them sticking to the norms of their office when they act, and if they violate those norms they might violate
* like the legit. This a non political type of legitimacy like they're empowered to do so. But they've undermined some important
* normative contract.
* 

**Lauren Taylor**

54:13

Awesome guys, we have 3 min. So I'm gonna ask for, like one to 2 sentences on the thing you'd like to underscore from your essay or the new thoughts since you completed the essay. And maybe I'll come to you first, Melissa.

* 

**Melissa Creary**

54:28

Sure.

* II think one of the things I'd like to underscore. Is this
* structural? Yes.
* That's really hard to to get at
* in our attainment, to trust that.
* just the ways in which
* you know research. Has a 5 year timeline. and that it takes 2 to 3 years to build trust.
* I one of the things I want us to think about in terms of like shifting
* the dynamic towards
* deeming greater trust is, how do we change the structures? How do we change the institutions?
* Which is the bigger.
* you know, existential question, and it's a much harder thing. But that's I think that's the thing I want us to get out of. But we have to do more than the superficial interventions we have to change. We have to shift the structure
* and we can't just talk about how we need to shift the structure.
* 

**Lauren Taylor**

55:34

Thanks, Melissa. I'm gonna insert myself here. Mine would be. Although everyone is very interested in building trust. I think in some cases we should recognize that mistrust is deserved, and we should respect it and not try and change it.

* Heart tick
* art. Michelle Deirdre Leah, like one sentence apiece, if possible.
* 

**Arthur Caplan**

55:54

Well, I think the only way to get better trust in terms of the communication issue is for the public to see more scientists speaking and more doctors speaking outside their classroom or outside their clinic. So I'm still big on grassroots communication about what science is about how it works.

* 

**Lauren Taylor**

56:21

So

* 

**Michelle Chau**

56:23

I think, maybe one of the big points that should be underscored from our essay is that you know, with, you know, this community organization serving as trusted messengers that

* the process is dynamic. And you know the trust that the trust building that's going on between health organizations and Cbos and Cbo's and community members has to constantly kind of keep going, and it has to be bidirectional as well like. Each party has to feel respected. They have to feel they're being valued. That.
* You know. There, there's something valued in this relationship, and they're they're each responding to each other. And that just needs to continue
* 

**Lauren Taylor**

57:05

Eardra.

* 

**Deirdre Mylod**

57:07

We didn't go into segmentation in our essay. But what I would emphasize is, we're often asked. Well, are there different drivers of trust or different drivers of likely to recommend for different identity groups. And generally, what we find is that people all need the same thing. They need to feel safe. They need to listen to. They need to be respected. They're not getting the same things, and when they don't get them it can have a differential negative impact on them.

* So that kind of just, I think, helps us move a little bit forward to don't spend time seeing. Or is this a unique group that has unique needs assume that people have some universal needs, and it's our job to fill them. And we're probably not filling them already.
* 

**Leah Rand**

57:46

That's a really good lesson, for where my question still sits, which is a lot of trust, is focused on these interpersonal relationships, where we have the opportunity to be in same room, and it's hard often to then think about how that scales up to something like a regulatory agency. But, dear, you remind us that there are some universal shared interests that we can still be working towards.

* 

**Lauren Taylor**

58:12

I wanna thank you all so much. This has been just a delight to a see you all again. And B get to kind of celebrate the work that we put into this.

* With that, I think I'm gonna close this out and just remind people who are here that are recording will be available, and you can share it with friends and family. I know everyone is gonna wanna put this up over the holidays and make sure
* their family can tune in and just once again thank Hastings Center for hosting this. Have a great afternoon. Everybody.
* 

**Briana Lopez-Patino**

58:52

Alright! Thank you for attending our webinar. A recording will be available shortly. Thanks again.

* 

**Melissa Creary**

59:00

Thanks. All.