

**What Happens Next – Sunday February 28, 2021**  
**Bioethics, US-Israel Relations, Selling the Museum's Art, and Who is White?**  
**Jacob Appel and Jonathan Moreno**

Larry:

My first question goes to informed consent. We did a book club on boilerplate language a few months ago, and it seems to me that the informed consent documents that you said were written by lawyers, and I'm sure they were, are provided now in every medical experience you have, whether it is in the hospital or at a doctor's office. There's this piece of paper, sometimes multiple pieces of paper, and they ask you to sign every one of these things. Otherwise, they won't treat you. Do you find the whole informed consent to be completely bogus on its face? Because one, nobody reads the informed consent documents, and second is that, if you did, you still have to give up your rights if you want care.

Jonathan Moreno:

In the research realm, in clinical trials, we're much better in general at informed consent than in regular clinical care. This is ironic, but because there have been so many scandals and tragedies about human experiments, that's a setting in which informed consent, I think, is pretty good. For the lawyers and for administration, informed consent has to be reduced to a piece of paper. I understand that, but it works pretty well, except, and this is more Jacob's domain than mine, I'm not a physician, but doctors are not paid to spend time talking to their patients. In a clinical trial, that is supposed to be part of the deal. But it's really hard to have an in-depth conversation when you're expected to see four or five patients an hour. So, I think the problem is bigger in the clinical setting than it is in the research setting.

Larry:

All right. I'm going to ask a question to both of you on this one. Let me start with Jacob. In our previous discussions about vaccines, I asked you the following question: should we inject the virus directly into patients to find out what would happen? I suggested that we could pay them, we could reduce their prison sentence, or we could ask for volunteers. And you mentioned to me at the time that that was against what you viewed to be a current view of what medical ethics was all about. Since then, the United Kingdom has announced that they're going to do just that. They chose volunteers, and they're going ahead with that sort of determining the efficacy of vaccines.

I'll repeat the question again now that we have a real experience with this, should the United States, if we condemn this method of science, should we be allowed to look at the UK results? Should we consider it if we don't support this type of experiments for moral reasons? Because if we do consider these experiments, then all we're going to do is push these experimentations to be done outside the United States.

Jacob Appel:

Sure. My initial thought is, even though I know the British are running a small human challenge trial, we probably are not at the point where we need to do that yet. And we should give it some pause, because even if we do this study perfectly, we want to understand the implications for how people perceive healthcare and perceive particularly vaccination, and particularly in communities that are often not considered or often are underrepresented. Anybody in your audience interested in the issue of minority attitudes towards vaccination, I urge them to read Harriet Washington's seminal book, *Medical Apartheid*.

That being said, and although there is certainly a long history of people engaged in illicit or immoral conduct as researchers having their data used, I think in the framework we have now, if we have the data, we're hard pressed to tell ourselves, "Well, we have it. We shouldn't use it because we're going to encourage others to do it," if it can save lives. It's a balancing choice.

Jonathan Moreno:

When this was being discussed last year the goal of challenge studies for those who advocated them was to accelerate vaccine development. Well, we have vaccines now, so you don't have that argument anymore. I believe that the study in the UK is one that has to do with the dosing level. It seems to me that's also getting pretty hard to defend these days. There is a long history of challenge trials. I think they could be justifiable in certain settings. Big problem here is that we don't have therapies in place if somebody does get really sick. So, I think it's really hard now to justify a challenge study.

Larry:

Let's imagine that we're interested in learning about combinations of vaccines and boosters. We want to know if we can use the Moderna with the Pfizer or the J&J with Pfizer, or with whatever, and we also want to understand how that will work or not work with variants.

Imagine that the South African variant hits the US shores and we see a second spike. Don't you want to know what combination of vaccines is best? And if we can save hundreds of thousands of lives, aren't you willing to bend your ethical rules?

Jacob Appel:

I would say there certainly is a tipping point, but I'd have to be very sure that we're saving hundreds of thousands of lives by doing it. You can always construct that sort of scenario. Where we can now, though, we have lots of advances in vaccines, and at nearly the same level of advances in therapeutics, it would be very hard for me to see a scenario where we justify a challenge trial.

Jonathan Moreno:

Yeah, I think you'd get some biostatisticians together. I think that a number of those folks would say, "You can actually figure this out based on getting massive data from the populations that are getting the different vaccines." So, I'm not sure you could justify it. A big population study could probably give you that information, I would think.

Larry:

But let's imagine that the big population study would take six months versus takes six weeks. We know, if we have to shut our economy down, we'd have trillions of dollars of loss. Schools have to be closed again. A whole generation of students will be denied their educations. There are significant consequences to all of this. You may not need that many people to be given the virus to know.

Jonathan Moreno:

It's hard to deal with a hypothetical like that, Larry.

Larry:

Okay. I'll move on.

Jonathan Moreno:

Hard cases don't always make for good ethics. I would punt at this point. I would say, "Let's see how this develops." You're not going to be able to get an answer to a comparative challenge study of different vaccines right away, either. That's going to take a while.

Larry:

But I was surprised there wasn't a widespread moral outrage at the UK's studies. Why do you suppose that was?

Jonathan Moreno:

I would say that's because the challenge issue is behind us now. It just doesn't seem to be as relevant at the moment. We'll see what the reaction is. I don't know what the reaction is among colleagues in the UK, in the bioethics world, but it just doesn't seem to be as present right now as an issue. By the way, they're taking 90 subjects, which is interesting because, if you had 100 hundred people and you had a 1% chance of a bad reaction, that would not be good. I wonder if they chose 90 deliberately to keep the likelihood under 1%, even for these young, healthy volunteers.

Jacob Appel:

Yeah. I think it's important not to forget the optics. We talk about the benefits of these sorts of studies. One terrible study or one terrible outcome can change the future drastically. You could

think, for example, about gene therapy, and have the death of one patient transform public attitudes for a decade.

Jonathan Moreno:

Yeah, exactly. It was my institution, Penn, unfortunately, that had that episode, and it did stop gene therapy studies really for a couple of years, not only in the US but around the world. So, one death, really, this is a bad environment in which to have a problem like that with a vaccination study.

Larry:

I want to go back to Jacob's ideas about who we should vaccinate and when. Yeah, I think you're right. It does seem pretty chaotic right now with different states having different criteria. How would you feel if we just came out with a first come, first served, and get rid of all the criteria? Is that more ethical, or is that a better type of policy?

Jonathan Moreno:

Big problem is many people can't get there. So, if your goal is to save as many lives or as many life years, and there's a debate about that, then you're not going to do it that way, first come, first served.

Jacob Appel:

First come, first served systems tend to favor the well-off, White populations. You could talk about a random assignment, but a random assignment, like lottery tickets, wouldn't save as many lives as possible. I do think there's something to be said for the system Connecticut has recently adopted, where they're simply lowering the age in a three-week cycle, because that's very regimented. Whether you're an essential worker or not is somewhat controversial, it's subjective. Whether or not you're 54 or 55, we can look at your driver's license.

Jonathan Moreno:

I spent a couple of months in the beginning of this thing doing what I should have done many years ago, which was reading every book about pandemics and epidemics, written by good historians, that I could find. As one of them said, if you've seen one pandemic, you've seen one pandemic. So, as much as we hope we can learn from this experience, if there's another one, it's going to be a little different. We're just going to have to develop a system that does not create as much mistrust as this one, but it will be determined by the variables of that situation. West Virginia, by the way, interestingly enough, a contrast to Connecticut, is doing pretty well. And they're in a very different setting from those Northeastern states.

Tevi Troy:

This is Tevi. What was the best one of those books that you read? I'm just curious. And what lesson did you take from that book?

Jonathan Moreno:

Oh, wow. We'll have to have an offline conversation. There are so many good ones. There's one about the history of cholera. There's one about the plague in the 14th century. There's some great writing about the way that smallpox was eradicated by WHO in the 70s. There's a lot of good ones. I would hate to pick one out, because again, each situation is pretty different, and there are different lessons to be learned from each.

Charles Rosenberg, *The Cholera Years* -- This is a classic by one of the founders of my history of science dept at Penn.

Gina Kolata, *Flu* -- By the NY Times senior reporter who brings a journalist's eye.

Frank Snowden, *Epidemics and Society* -- By an emeritus Yale prof, excellent overview up to and including Ebola.

Larry:

Jacob, question for you about one of your points about compulsory vaccines. We, as a community, have demanded compulsory vaccines in the past, particularly as it related to students who go to public schools. Do you think that there is a justifiable public requirement for this, whether it be at work, at school, or for travel, to allow our economy to come back to work and to minimize potential contagion in our Society? Or do you think that the individual liberty arguments, of freedom of choice of families and individuals to choose whether or not to take the vaccine, dominates at this point?

Jacob Appel:

Sure. I don't think we're at the point where we can even answer that question yet. Obviously, I think people who know constitutional law know that it's clearly legal for us to mandate vaccination. We could make people do it, but doesn't mean we should. We'll have to figure out what percentage of people will do it voluntarily, where that puts us on the herd immunity graph, and whether or not we can keep the public safe without compulsory vaccination. But we also have to ask ourselves, if we were to oppose it, how stringent would we be, and how we would enforce it? We don't want to run the risk of excluding certain minority populations who are more vaccine-hesitant from society, and I certainly imagine the prospect of locking people up for not getting vaccinated would not be politically tolerable and would be highly disruptive. So, the verdict is still out.

Larry:

Just going to your point about that, if some minority group have less active vaccination rates,

why has that become an issue of fairness? In other words, if one group decides that they would, let's say, rather not get vaccinated and give up airplane travel, why should our society view that necessarily as unfair on either ground?

Jacob Appel:

Because excluding people from the public square, from schools, from airlines, from the economy, and there is likely to be a heavy racial overlay to this, will exacerbate the very inequalities we spent the last year trying to address. I think it's problematic to short change populations for generations, and even during the course of the current pandemic, to set up allocation systems of resources, in which, for example, the African-American and Latino communities here in New York City simply fared worse. And then suddenly, when it's in the interest of the White majority to have people vaccinated, to turn the tables and say, "We didn't help you, but now you owe us." That should really give us pause.

Larry:

Do you feel that this decision should be at the individual, corporate level, or is it a societal question? In other words, let's say a business would benefit by having an all-vaccinated restaurant. Could they make that demand, or do you feel that is not a decision that individual businesses can have? And if it's at the commercial level, do you also feel, let's say that I'm having a dinner party and I'm inviting everyone. Could I write, "Anyone could come who's vaccinated." Would that be also viewed as a violation of public policy and trust, or unethical in any way?

Jacob Appel:

For your own dinner party, you can make any arbitrary choice you want. You can invite people who are like you, you can discriminate against race and religion. There are certain spheres we think are so private we don't want to intervene. Once you talk about businesses and commercial enterprises, we really want to make sure that anybody feels comfortable walking into a store or a restaurant and not being second-guessed. Otherwise, among other risks, you'll have a risk of profiling. If certain communities are less likely to get vaccinated, there may be suspicion of those people, even those who are vaccinated, when they engage in the use of public services, and that would really be a problem.

Jonathan Moreno:

At the hospital, this is Jonathan again, I wonder what Jacob's hearing about his own institution. My colleagues at Penn and former medical students are telling me that they know that there are a number of people in support roles in their hospitals who are vaccine-resistant. Maybe it's a quarter, and they are often people of color. So, I'm wondering what Jacob's experience is with this in his own hospital.

Jacob Appel:

Oh, I think it's a real challenge. But it's worth noting it's been a real challenge before COVID. A majority of states don't require flu shots for health workers, and some don't require masks, and yet, for the average person going into a hospital or a nursing home, you don't think you're going to get the flu from healthcare worker. This just magnifies it.

Jonathan Moreno:

Yeah. Another one from Jonathan for Jacob. Do you think this will pass? Do you think that, six months from now, most people who were in support positions in hospitals will have been vaccinated?

Jacob Appel:

Before I started talking to people about this, I would've said yes. I've had enough conversations now with colleagues, some of whom I deeply respect, in various roles, not just ancillary roles but direct clinical roles, who are deeply resistant and it can explain very logically and meaningfully why they're resistant. Even though I disagree with their premises, once they hold those premises, it's very hard to shake them.

Jonathan Moreno:

Yeah, yeah. I think that's right.

Larry:

Let's imagine that a state views that to be illegitimate, that we have patients in the hospital who if they COVID, they will die. And yet, these, I'll call it, non-vaccinated individuals who may be carrying COVID are coming into the hospital and potentially infecting patients. Should the state require hospitals to have their staff be vaccinated in order to protect our most vulnerable patients?

Jonathan Moreno:

Well, hospitals are pretty buggy places anyway. Right? It's not a place you want to be very long, whether it's COVID or something else. So, these infections that are related to being in a place where a lot of people are sick, it's not something new. I don't think it should be treated differently. It's definitely a concern, but you don't want to send the message that hospitals are forcing people to be poked. I think that, in general, that's not the way we want to go. We want trust; probably not the way to achieve it.

Larry:

Well, let's try a different example. We understand that nursing homes are very vulnerable places, and we've limited who can go in and out of those nursing homes. How would you feel about requiring vaccinations of nursing home employees?

Jonathan Moreno:

Well, so, you're talking to somebody whose mother was in a couple of nursing homes. It's definitely something that I thought about a lot people, coming in and out, not only the workers, the aides, but other patients being around her. It was a concern, I won't say it isn't. And yet, I wouldn't want the people who were taking care of her to feel as though they were being forced to do something that they had pretty good reasons not to want to do so. It does put more of a burden on infection control in nursing homes. Many nursing homes are good at that. I think that's where you go with that.

Larry:

And let's say that the nursing home themselves said something like, "If you want to work here, then you have to be vaccinated. I'm not saying you have to work in a nursing home; you can get a job somewhere else. I can't risk killing these elderly people." We know, for example, that sometimes vaccines are more effective with young people than older people, and that they're incredibly vulnerable to these diseases. Look, I'm not saying you have to get it, but you don't have a right to work here. You're an at-will employee. Should it be the company that make that decision and not the state?

Let's imagine there's more profits. I can offer a nursing home where everyone is vaccinated, and that my competitor's offering a nursing home where I don't know who's vaccinated. I'd send my parent to the one with the vaccination program.

Jonathan Moreno:

Oddly, residents of nursing homes tend to be people who have more of a choice than the people who work, about where they choose to work. So I would say the nursing home should make it clear what their policies are about infectious disease, and families and potential residents can take it from there.

Jacob Appel:

Fortunately, I don't think we're going to face that choice with COVID going forward, because I think that, if you've asked me if the nursing home residents were going to have enough resistance, that they're really not going to be at risk of severe illness for the kind that we're worried about.



Larry:

All right. Let's try the public schools. Historically, we have required students to be vaccinated in public schools. Do you think it makes good public policy sense to require vaccinations of children in our public schools? Jacob?

Jacob Appel:

From an ethical point of view, I can see a scenario where that would be desirable in the long run, once there's more faith in the vaccine, but when you have poll data showing that 20, 30, 40% of people might turn down the vaccine, particularly for their children, you don't want a scenario where 40% of the public doesn't feel comfortable sending their kids to public schools, so I don't think we're anywhere near that yet.

Larry:

I don't know if we had similar surveys for MMR or polio or whatnot, yet we've gone ahead and done it anyway. To my knowledge, they've gotten the kids vaccinated. Why do you think that, if given the choice between sending your kid to school, that they would be so adamant that they would choose not to do that? And alternatively, why don't we just create a virtual school for those children who are unwilling to take the vaccine in the meantime?

Jonathan Moreno:

Well, I taught at the University of Virginia, that definitely had students who came from homes where the parents decided to have them homeschooled, not only for vaccination but for other reasons of the kind of values they didn't like, that might've been transmitted in their kids' education. But I think, when it comes to public schools and vaccination, this sends an important message. It is evidence-based, and I think people need to be comfortable going into a public school.

The polio case is interesting, Larry, because, if you look at the history of polio, kids were lining up in droves to get vaccinated. In the beginning, it wasn't at all clear what would happen to them. In fact, 10 children died because of a bad lot of vaccines from a company called Cutter in California, which is still cited by people who are anti-vaccination. So, the polio case was one in which there was a real sense of civic responsibility to go out and get vaccinated as soon as possible. It was not only willing, there was a real demand for it in school districts.

Larry:

Well, I'm sure there's a real demand for COVID-19 vaccines among kids as well. There may be some children that don't want it, but there's others, I'm sure, who would be lining up.

Jonathan Moreno:

Yes, and I would be perfectly happy with that once we had better sense of how kids are responding to being vaccinated. I think we're getting good data now that shows that that's fine.

It's really a matter of supply, not demand, at this point.

Larry:  
Jacob?

Jacob Appel:

Yeah. I think the idea of having 40% of the population send their kids to virtual school long term unsettles me for its sociological impact. But I think you asked about the poll data. I don't know the date offhand, but anecdotally seeing lots of patients and colleagues, there were a lot of people who were perfectly comfortable getting vaccinated for polio and measles but still aren't ready to get vaccinated for COVID, and that plays into my calculus.