

**ELSI Friday Forum  
Migrant DNA: Context, Ethics and Legal Issues  
Friday, March 12, 2021**

TotalCaption - Captioned stenographically by Joshua Edwards, RDR, CRR

>> Sandra Lee: All right. Good morning, afternoon, or evening for those of you who are Zooming in. I'm Sandra Lee and I would like to welcome you to the ELSI Friday Forum. As you may know, ELSI Friday Forum is held on the second Friday of every month for one hour starting at 12:00 noon Eastern time.

You should also know that immediately following this forum, we will hold a post-event discussion in a separate Zoom room. And the link will be dropped in the chat. This is an opportunity for informal conversation that builds on the forum discussion.

As a reminder for those of you who are joining us for the first time, ELSI Friday Forum is organized by the Center for ELSI Resources and Analysis, or CERA, which is a multidisciplinary, multi-institutional center that provides resources to support research on the ethical, legal and social implications of genetics and genomics otherwise known as ELSI, and serves to connect a community for scientists, scholars, policymakers, journalists, members of the public and others to engage ELSI issues.

CERA is funded by the National Human Genome Research Institute at NIH, and is managed by teams at Stanford and Columbia Universities in partnership with the Hastings Center and Harvard University. CERA's online platform, [ELSIHub.org](http://ELSIHub.org) which launched in November, has a range of resources including the recordings and transcripts for all of the forums, associated reference material, as well as an ELSI literature database, a research instrument repository, a scholar directory, news and events and much more.

And I encourage you to go to the website to sign up for newsletters and other events like this one at ELSIHub.org, and to receive daily updates and news on Twitter at ELSIHub.

We are pleased to announce the publication of a new addition to our latest content series, ELSIHub Collections. Please use the link in the chat to access Race, Genetics and Genetics Education, a collection of scholarly work curated by Brian Donovan and Daphne Martschenko that explores the intersection of genomics literacy and racial prejudice. And We are recommending this reading list to those engaged in antiracist approaches to teaching genetics.

Okay. So now for just a few housekeeping details, if you wish to use closed captioning, please turn on the CC button at the bottom of your screen. We encourage an active exchange of ideas between our panelists and all of you. The panelists' presentations will be very brief, so we hope to use a significant portion of our time in discussion.

You can ask questions by using your Q&A button which you will find at the bottom of your screen. And you can register your enthusiasm for a question and elevate it up the list by using the upvote button in the Q&A box.

The chat box is available for further engagement where you can also find links to resources that are referenced in today's discussion. If you have any questions, please e-mail [info@ELSIHub.org](mailto:info@ELSIHub.org) at any time. So now it is my pleasure to introduce my colleague Paul Appelbaum who is the Elizabeth K. Dollard Professor of Psychiatry and Law and the Director of the Columbia Center for Research on Ethical Legal and Social Implications of Psychiatric Neurologic and Behavioral Genetics. Dr. Applebaum will be our moderator for today's event and I will now turn it over to Paul who will introduce our session.

>> PAUL APPELBAUM: Thank you, Sandra and hi, everybody. Thank you all for joining us today. Sometimes these Friday Forum sessions focus on familiar topics that

are at the front of all of our minds. For example, racism and the ways that misunderstandings of genetics can promote it or COVID-19, and the ethical issues that arise when genetic technologies are used to combat it.

Today's topic, the use of genetic testing in the context of immigration, is a much lower visibility issue, but it raises questions of ethics and policy that are no less difficult and no less profound.

One of the two pilot awards that's being funded currently by the CERA, the center for ELSI resources and analysis, the sponsor of these sessions as you heard, focuses on the ways that genetic testing is used or can be used in the American immigration system. And today we are going to hear two presentations about these issues, and then with your help, we will explore them with our speakers.

So let me tell you who we are going to hear from today. Our first speaker will be Sara Katsanis who is a research assistant professor of pediatrics in the Northern Feinberg School of Medicine where she's been since 2019. Sara's research focus is on policy options for genetic testing applications in medicine and in law enforcement, and how genetic technologies affect individuals.

She's also the principal investigator of the genetics and justice laboratory at the Lori Children's Hospital in Chicago which explores the policy science and ethics of genomic information for identification purposes and she's the PI of the CERA pilot award on border DNA.

Our second speaker after Sara will be Vera Eidelman. Vera is a staff attorney with the American Civil Liberties Union's speech privacy and technology project where she focuses on litigation and advocacy to protect free speech online, on the right to protest and on public access to secret algorithms used in criminal trials.

Vera is a graduate of Stanford University and Yale Law School, and we are delighted to have both of them with us today. Our speakers' brief presentations will be followed by a moderated discussion as I pose some follow-up questions to them, and then we will open it for audience participation, your questions as you heard can be written into the Q&A box.

And I promise to try to get to as many of them as is possible to include in our discussion. Now let me turn this over to Sara for her presentation. Sara.

>> SARA KATSANIS: Thanks, Paul. First of all I want to thank the ELSI Friday Forum organizers for inviting us to present today on this obscure nonmedical ELSI topic and please note that some of the research I will discuss today is supported by an NHGRI grant. And the content of this presentation are my thoughts alone and not those of our sponsors or any of our affiliated organizations. Next slide.

You might have seen in the news at some point in the last several years articles covering the use of DNA data collection in immigration. And in order to understand the ELSI ramifications, what I would like to do is break down the scenarios by use category or use context based on the societal -- so we can better explore the societal implications.

A few years ago when I proposed the NHGRI grant, there were only two contexts in which DNA data was being used in immigration. And now I count at least five contexts. Maybe we can debate if there are more or fewer, but I am going to present these five today. Next slide.

>> First is the commercial use of DNA to test family relationships. In fact DNA testing is not a new topic. Next slide. The very first publication of the use of genetic markers for an identity test back in 1985 when Alec Jeffries published was an immigration test. It was a case of a migrant mother petitioning for her child to join her in the U.K.

Today if you search the internet for the phrase "immigration DNA," the majority of the hits you will get are for the commercial offerings of such DNA tests which are very commonly requested for family petitions. And in some circumstances required like for a priority three refugee petitions for family reunification. Next slide.

The second context is the collection of family reference sample DNA data for the identification of missing persons across international borders. In the U.S., hundreds of migrants die crossing the southern border each year and most of the human remains are never identified. Missing persons DNA identification relies on the acquisition of DNA from the unidentified human remains to be compared to DNA from acquired family reference samples from relatives of missing. But because of transnational missing persons cases across international borders and involve missing persons reports that are part of law enforcement in the United States, there are a number of challenges with DNA data collection and sharing. Next slide.

Some deceased migrants, particularly in Texas never had DNA taken and are buried or cremated without ever having been identified or sampled. Some of these unidentified remains of migrants might one day be exhumed in an attempt to identify them, but many burial sites will never be located at all. Next slide.

CODIS which is the combined DNA index system is the federal database for sharing DNA data among U.S. jurisdictions. And they include separate unidentified human remains indices that can be used to compare for matches or kinship matches and potential identifications. But both of these database also underpopulated. Some postmortem DNA specimen are sent to a private laboratory instead of to CODIS to be compared to foreign collected family reference samples.

Family members of the missing might be fearful of reporting to law enforcement particularly if they are undocumented or recent migrants. So many families

might opt to provide DNA to NGOs, nongovernmental organizations who they might trust more than police. Most families never provide DNA at all to any authority.

The result is scattered efforts and fragmentation of the UHR and family reference sample data in different databases. With federal policies that prevent -- that govern CODIS that prevents the DNA data sharing among these parties. Next slide.

The third context is use of DNA tests to reunify families separated by the government during migration. You might have heard conversation of this back in 2018 when migrants children were forcibly separated from their parents coming to the United States. Next slide. The use of DNA data by the government for finding or tracking the children that were separated from their families prompted strong support and also strong backlash simultaneously, and mostly along political lines.

Today over four hundred families remain separated. It remains to be seen now whether DNA data might be useful for reunification of these families, and especially if that data can be managed outside of the government. Next slide.

The fourth context is use of so-called rapid DNA tests at border entry points to verify claimed relationships. Next slide. I am going to present a little bit of a backstory for this context. In 2014, the United States witnessed a surge of unaccompanied minors entering the country particularly from Central America which prompted the conversations of how and whether data can be useful in verifying identities of the sponsoring relatives. Next.

Since then, the unaccompanied minor immigration trends have fluctuated, but remain relatively steady and at pretty high numbers. In January of this year, the HHS requested comments on the potential use of DNA test for verification of the sponsors that unaccompanied minors might be placed with. Next.

Then in 2019, the U.S. saw a record number of family units entering the United States. These numbers dwarfed the minor migration trends that we saw back in

2016. This prompted DHS in May of 2019 to conduct a pilot of rapid DNA testing at border entry points to verify the parentage claims in parent/child family units. In 2020, DHS proposed a broad biometric program that was expanded and funded and systematized rapid DNA testing for families including the retention from those family tests. This proposal was not published as a final rule, but highlights the value that they place in the utility of DNA in verifying families. Next. And just this week, news has come out that the Biden administration is struggling to manage a new surge of migrant children.

It's possible that DNA data might continue to be of value in managing migrant family influx. Next slide. So the goal of the rapid DNA family verification program was to detect immigration fraud and/or human trafficking among the family units being screened at U.S. border entry points. The rapid DNA instrument would enable quick processing of specimens within two hours to test those parent/child relationship claims. Next slide.

This practice, however, this ongoing practice lacks transparency as in, we do not know how the family units are selected for testing. We don't know the parameters for managing the negative test results, those that do not have a family relationship or genetic or biological relationship. And we don't know the outcomes of those cases.

This is especially important since we geneticists and we ELSI scholars here in this virtual room recognize that not all families are genetic. Next slide. Finally the fifth context is the collection of DNA for the criminal database from migrant detainees. Next slide. I thought a time line could help for this context which starts with the 2005 DNA Fingerprint Act which expanded the authority of the federal criminal database CODIS to include DNA data from non-U.S. persons detained by a federal agency. Next. In 2008, the DOJ proposed and finalized the rule to enable this policy. Next. In 2010, the Obama administration requested a waiver through DHS which was justified by the lack of infrastructure

for DNA sampling. And the difficulty in coordinating data and sample exchange between DOJ and DHS. Next.

Fast forward to 2018 when whistleblowers filed a complaint that CBP was negligent in their legal requirement to collect DNA from immigrant detainees. Next. In August 2019, that complaint was considered founded, and it was noted that the 2010 hold was supposed to be temporary. Next.

In October of 2019, a proposed rule was announced to lift the waiver and by the end of 2020, just a couple months ago, the phase in of DNA collection was completed. Next. So during this time line, despite the waiver being in place, the CODIS detainee index was growing, but only by about 15 hundred to three thousand individuals per year which is a minuscule number considering the hundreds of thousands that entered the U.S. each year.

Next. This last year in 2020, during the phase-in of the newly reinstated policy, DNA data was collected from about 13,000 individuals for this index. Next slide. It is important to point out that the CODIS detainee index is not used for border control. DHS which means ICE and CBP, they do not have access to CODIS and cannot search the database for repeat border crossers, for example.

DHS has long been saying that they are developing a surveillance DNA database likes the HART database for immigration purposes, but CODIS is not that database. CODIS is used currently only for criminal justice purposes. Next slide. I present these contexts today because as society advantages from genetic applications that can also be used against them, it's important that we correct misunderstandings, misinformation, and depoliticize how science and DNA data are used.

This is really important to draw these lines. It's not simple to draw lines between these overlapping uses of DNA data and genetic data, but it helps to differentiate



as we are developing policy solutions. Next slide in my last few seconds, I want to highlight the work that the CERA program is funding for our team.

We developed a working group comprised of academic scholars and students and one immigration attorney to develop informational resources to describe three of these contexts that I've highlighted today and to communicate the nuances of how genetic information is being used. Next slide. Our first two products are going to be infographics that we will release in the coming weeks.

The products that we've developed over the last couple of months have been embedded through expert consultants and are designed to be informational and unbiased. Next slide. We are also developing animated videos for each of the three contexts for the lay public which we hope will be ready for the summer. Next slide.

And finally, I just want to thank the many scholars that work alongside me and advise and guide our team. This kind of ELSI research requires many, many, many perspectives, thoughts, and ideas to navigate and not just my own. So thank you. Next slide. Next up, I would like to introduce Vera Eidelman who is going to talk some more about some of these immigration DNA issues.

>> Vera Eidelman: Thank you so much, Sara. And I look forward to seeing all of those resources as they come out. As folks mentioned, I'm Vera Eidelman. I'm a staff attorney with the ACLU speech privacy and technology project. I do not have any disclaimers to make except for the one that I always make which is that though I am an attorney for the ACLU, I am speaking in my personal capacity much like Sara saying what I think and not what the ACLU thinks. And the focus of my presentation today will be on some of the common issues raised by government collection of DNA. So Sara talked about five contexts some of which included private collection NGO collection and I'm really focused on government collection. Next slide, please. And so just to tell you about my quick

presentation, I wanted to start quickly with history as context which I think is helpful for understanding some of the common issues I will talk then about the final rule that Sara already touched on for forced DNA collection from folks in immigration detention. The Trump administration's proposed rule for expanding biometrics collection, from people seeking immigration benefits, and then the common ethical legal and I should say social implication questions that are raised by how I think about this. Next slide, please.

So first in terms of thinking about history as context here, I think an important lesson to learn from our American history of surveillance technologies generally is that the government often uses the border and immigrant populations as a justification for introducing normalizing and expanding surveillance.

The government essentially sees the border as a space in which it has much more authority than it has internally and particularly the executive. And a lot of the work pushes back on that, but it is a justification that often gets used for example to search electronic devices at the border, so meaning your cell phone or your laptop without a warrant and perhaps even without suspicion.

Drones that the Department of Homeland Security initially instituted at the border are now used internally, including to surveil protests throughout the summer. We've seen it with face recognition and more. And once that surveillance infrastructure exists, not surprisingly, it gets used. And perhaps less intuitive, it also frequently gets expanded, especially as technology makes the surveillance cheaper and easier to use.

And that, too, is something that we have seen throughout history with technologies. It's what happened with wire tapping which initially was introduced as something that was only necessary for very specific and serious crimes and purportedly would be so onerous that it wouldn't be used very often. It gets used very often at this point.

The same is true with cell phone location tracking and DNA databases are a very good example of this, too including CODIS and state and local databases which initially were meant to collect DNA from individuals convicted of very serious crimes. Then the definition of those crimes got expanded out. Then in some places, it expanded out to folks who were just arrested for certain crimes and as we are talking about today, it is now used to collect DNA from individuals in immigration detention. The other piece which is slightly less relevant to what we are talking about today is the technologies also start to get used beyond their bounds of verified or validated applications. So with rapid DNA for example which we talked about in the family unification context, those same -- actually, Sara can correct me.

But it may be actually different rapid DNA tests. But tests that really are for single-source DNA samples have been used by local precincts and local police departments to try to solve crimes. For example, looking at complex DNA samples which are not a validated use of the technology. So the point here really is that once we allow certain surveillance infrastructures to exist, even if we are doing it for a particular purpose, often what will happen is that it will get expanded, the purposes will get expanded and it will even before they technically get expanded potentially get used beyond those purposes. Next slide. Please. The other piece I think that's useful to recognize here is I think as folks already mentioned earlier today, throughout our history the government has also relied on perceptions or perhaps misperceptions about genetic and other health information to discriminate in everything from marriage to employment. Currently the slides says USCIS allows officials to deny lawful permanent residence status to immigrants who are likely to need public assistance. Fortunately that no longer true. The earlier this week a court ruled that cannot be enforced. I think that's a good example of the way in which the government sometimes wants to use health information, for example, denying legal status to people

who are likely to need public assistance including in the medical realm. And the other thing I think that's useful to keep in mind here is because of the reality of policing in our country, people of color are often overrepresented in surveillance databases, including in CODIS which again as we mentioned, included people who are convicted and arrested for certain crimes.

And because Black people and other people of color are generally policed more, typically they are much higher numbers of Black people and other people of color's DNA in these databases. And the same will and is ending up to be true through the expansion of DNA collection to the immigration context.

And because of the way the databases are used as Sara mentioned in the criminal context, that means that people of color are more likely to be implicated in criminal investigations in the future. Next slide, please.

And so just to talk a bit about some of the specific rules and contexts that we are talking about today, with the forced DNA collection in immigration detention rule that was proposed a couple of years ago and as Sara mentioned is now being fully enforced starting in December of 2020, the government's purported justifications for this were to identify people in detention, to calculate risks for facility staff and others in detention, to inform their detention decisions and is to solve past crimes. And I think a really helpful framing question when thinking through these justifications is first is it necessary? Which is the third point on the slide. Given the amount of information that's already collected about people in immigration detention, is DNA really necessary to know who they are, to understand the risks and the facility?

And even if it is and if we think that these justifications make sense with respect to DNA collection, what would we think about a universal DNA database for these purposes? Because even if you think, you know, okay, fine, it probably will help solve past

crimes. But does that mean it certainly would help solve past crimes if everyone upon being born in the country became part of a universal database.

And I think it helps us think through our intuitions. My intuitions you will be shocked to hear is I am not interested in a universal DNA database. To me that seems to pervert a lot of the trust and freedom that I think our society is built on. But people may not disagree with that. I just think it's helpful and -- may not agree with that.

But I think it's helpful to think through that possibility to understand what we think about collection from people in the immigration context. Because one of the reasons why we may think about it differently in an assumption that to me seems clear from the proposed rule and final rule for this is that the reason that we are willing to do it in the immigration context is that immigrants are somehow a danger to our society.

And I think that that's a concerning assumption and it's one that also ignores the fact that many people who are coming here are actually themselves victims of violence who have fled here and who don't, for example, want their DNA shared with the country that they have left. Next slide, please. And I think the expanded biometrics collection proposal which as Sara mentioned, the Trump administration proposed in September of 2020 is not clear what will happen with the Biden administration especially as, you know, we don't know what will happen with migration patterns, either. I think it's also a helpful real example of what type of collection is being -- has been considered and for what purposes. So this proposed rule would have presumptively authorized the collection of any biometrics including as Sara mentioned DNA collection, also voice scans, iris scans, face recognition from any applicant or sponsor for most immigration benefits. So right now very specific biometrics are collected for specific benefits. And this would have flipped all of the presumptions. It would have said for essentially all benefits, all people who were applying

and in most contexts people who are sponsoring them or in some contexts are being -- may be subject to a very expanded form of biometric collection.

And again, the purported purpose here was to do identity verification to conduct criminal and national security background checks, and the wonderfully nebulous, quote, any functions necessary for enforcing immigration and naturalization laws." I as a lawyer can't really even tell you what those purposes would all be.

And again, I think it's just worth asking is every one of these types of collection, are they actually necessary? Are they justified? And again, you will be shocked to hear I think this version is not necessary and I don't think it's particularly justified. Next slide, please.

So for me some of the common questions here are, is the DNA collection necessary or justified at all? I think another framing question is, is it voluntary? Because certainly there are some examples including some of the ones that Sara mentioned where for example, a mother wants to be reunited with her child. Should she be allowed to provide her DNA for that purpose? My answer to that I think is yes.

And I think it's a hard question in part because can the collection really be voluntary in these contexts? A lot of them are really inherently coercive. And so if I were to be given the choice between giving up my DNA and having access to my child, it doesn't feel like a real choice to me. That's not to say that that DNA shouldn't be collected for that purpose. But I think it's also then really important to think through what the limitations are on the use, access, disclosure and retention of the DNA. Who can use it? How can they access it? When can it be disclosed? How long is it retained for? CODIS, the DNA samples are retained forever, so past one's lifetime. Does that make sense? How are those limitations then enforced and monitored?

And what are the procedures for expungement? CODIS which as Sara mentioned is generally a criminal -- well there is the missing persons piece, but there's also, it is often used for solving or trying to solve crimes. And in the criminal context, if someone is acquitted of a crime or gets a court order, they can actually have their DNA expunged from CODIS. I'm not aware of an analog. That's important to me, if someone is improperly detained and they get put into the system, shouldn't they have a way to get out of it? Next slide. And that is the end of my presentation. Here is my contact information if anyone would like to reach out later and I look forward to our continued discussion.

>> PAUL APPELBAUM: Thank you, both, Sara and Vera, for those great presentations. We are starting to get questions in the Q&A. Let me encourage those of you out there to please put your questions in as well. But before we turn to those, just for a couple of minutes, let me pose some questions to both of you that may give you a chance to elaborate on some of the issues that you talked about.

So we heard a lot from Vera about the CODIS collection, and Sara mentioned that as one of five types of ways in which DNA is being used in the immigration context. But I want to focus a little bit of our attention on some of the other ways it's used. So, for example, it's being used at the border for rapid screening and identification of familial relationships.

And as I understand this one, the overjustification for it is that we want to make sure that trafficking of minors is not going on and to verify the familial relationships. So, question. How big a problem is trafficking of minors across the border? How effective are these rapid DNA tests in identifying it when it occurs?

>> SARA KATSANIS: We don't know the answer to either of those questions. So first off, there are anecdotal examples of children being trafficked across the border.

But I have not, when we say "across the border," through border entry points, I have not heard of any yet of children that were trafficked across the Mexican border.

So first off, we have some confusion in the policy realm and the journalism realm around the term "trafficking" versus "smuggling," because trafficking is the exploitation of children or people. And smuggling is when somebody pays to be brought across a border under illegal contexts.

First of all, both of those things do happen. Sometimes it's the same thing. But I have not heard of any actual sustained examples of what came out in 2019 as child recycling, with air quotes around that. And that was the supposed use of a child to go across the border and say this is my child; please can I have entry to the United States, under the presumption that there's better protections for family units than there are for individual sole adults crossing into the United States.

And then sending that child back to be brought again. And to me that's trafficking and that's exploitation and that would be terrible if that is occurring, if children are being poised as the child of a migrant. That's terrible and awful and that should be investigated. I haven't seen examples of that yet. There were rumors of that happening in the media, but none of those were sustained with any details that we could understand.

If it did happen, I would love to know what percentage. As far as the rapid DNA verification goes, we can't answer whether that's effective, either, because we do not know how many of those families are being selected. So the news reports were saying a third of migrants or a fifth of migrants or 20 percent of migrants were faked families. But the truth was they were selecting family units.

We don't know how they were selecting family units. What don't know what percentage of family units were selected and then testing those two people for their relationships. We don't know how many of those that didn't match the one third or 20



percent, we don't know how many were a legitimate stepfather and child that didn't clarify, no, no, no, I'm a stepfather before the DNA test was done. We don't know how many were uncle and child.

We have no breakdown or information on those cases or maybe 20 percent of those were fraud cases. We don't know because we don't have the information and details to understand better.

>> PAUL APPELBAUM: Okay, thanks. Vera, anything you want to add on that regarding the use of rapid DNA testing for family verification?

>> Vera Eidelman: I think I mean, I learned from that Sara, so thank you. I think those are really helpful and important questions to ask. And I think the other thing to think about is what information is already being collected from people at the border and whether or not DNA is then a necessary way to figure out or even a correct way. As Sara was saying, if we are not only interested in biological relationships, is it actually a useful test?

And given that already so much documentation and testimony is provided to verify family relationships, is it necessary? And the position that the ACLU has taken in our family separation litigation, for example is that it is proper to use a DNA test, but only if it is voluntary by the parent. And only if it is a last resort where there's a reason to dispute, to really believe that parentage is not in existence between the two individuals.

And we also again really care about the use and retention limitation. So only used to verify that relationship and then immediately deleted.

>> PAUL APPELBAUM: Let me ask one more thing before we go to the questions from our audience. And that is another use of DNA, Sara, that you talked about; namely, for identification of migrants who are found deceased in the Arizona desert or along the Rio Grande which somehow feels different from at first pass, it seems to be a use

that's aimed at helping the families of these migrants know what happened to them and have the bodies of their loved ones back to be buried appropriately.

Are there issues that we should be concerned about with that use of DNA? Are there reasons why families for example might be reluctant to give samples to allow matching to occur?

>> SARA KATSANIS: Yes. Thank you for bringing up this context because it's very close to my heart and something I have been concerned about for a number of years. Because missing persons investigations are run through law enforcement, the DNA data are going into CODIS. And that is the mandated way to identify missing persons and unidentified remains in the United States. Which means that these families of the missing, if they are undocumented, if they are living in Mexico, if they are related to somebody who might be undocumented, are afraid to come forward to help identify their loved ones. And that is where we have been stuck for the last decade with families desperate for ways to identify their loved ones and fearful and unable to work with the government to be able to protect their data so that they can identify their loved ones.

There are protections in place in CODIS that prevent family reference samples from being searched against criminal evidence, for example. But that's not enough to allay the fears of the families. And there needs to be other mechanisms to protect family reference sample data and to share data across organizations like with NGOs.

If an NGO runs a database, there's no protections for those data at all. CODIS at least has federal protections from it being used and misused outside of its realm whereas an NGO holding that data, that data can be subpoenaed, searched, hacked, many other ways to access. And we say this in demographic data already with NamUs. So it's certainly a risk for DNA data as well.

So we need CODIS and law enforcement to better cooperate with families and with NGOs and we need NGOs to have protections for their DNA data so that that data can be protected from misuse and abuse.

>> PAUL APPELBAUM: Great, thank you. So let's go to some of the questions from the audience. Vera, maybe you want to take a crack at this one. Someone asks, given that there's a strong chance that another change of administration could reinstate many of these discriminatory policies, what policies and legislation should we be advocating for at this time to prevent future harms?

>> Vera Eidelman: I think that's a great question and a very real possibility. So I think one is again just should we allow the collection at all? Because there's legislation that could stop that to begin with. I think others are again thinking through the limitations on the use, the retention, the access.

And I think that we are not where we should be. I mean, as Sara said for the missing persons piece of CODIS, but I also think more broadly, I don't think where we should be even more CODIS which is then actually far more regulated and regulated in a far better way than databases that exist at the state and local level which we haven't talked about at all.

So, for example, in CODIS, you are not through CODIS itself through the national database, there is not a way to conduct a familial search, though states enable familial searches of that same database at the state level. And familial searches to me raise an even broader level of ethical, legal and social implications, because as you all know better than I do, our DNA is networked.

And so the implications of having one family member's DNA in CODIS is actually very broad, could be very broad for other family members. So I think thinking is it even necessary to begin with, can we stop this kind of collection and stop these policies?

So, for example, the expanded biometrics collection rule, it went through notice and proposed -- notice and comment under the Trump administration, but did not become a final rule.

So pushing back on those rules before they even become final and if it is something that's going to happen, what limitations can be put on it?

>> PAUL APPELBAUM: And in general, there are these initiatives derived from new legislation or is this all regulatory rule-making that results in these policies?

>> Vera Eidelman: So it could depend. As Sara was saying a lot of what has happened so far came from the 2005 Adam Walsh act which defines the full scope of what could happen and then regulations exist to define the specifics. But certainly new legislation could be passed that is different, different from and better than the 2005 Act.

>> PAUL APPELBAUM: Okay, thank you. So Barbara asks, how does DNA in these contexts intersect with deliberations about whether DNA sequence data should be considered a biometric identifier under the HIPAA privacy regulations? Do either of you want to take that on? Sara?

>> SARA KATSANIS: Yeah, I would say that it's really important to differentiate the DNA data that is being used and the sample and retention and the potential use of that sample beyond the DNA data for short tandem repeats. Short tandem repeats we know do not have any biomedical applications, they are by design but also by nature because they are highly variable, they are not going to be connected to traits to any discernible ability.

But the samples themselves need to have the same protections and especially as we are developing sequencing approaches for looking at those STRs and for expanding to snips and now that we are seeing a lot more criminal justice use of snips for family comparisons in investigative genealogy, that's using snips that we all know are very well connected to genetic information that might be protected under HIPAA.

So I think that it is really important to examine that on the -- for any time a sample is being retained, not necessarily for forensic evidence because forensic evidence doesn't have such protections. But for missing persons and for family reference samples from missing persons, I think is really important to have the ability to interrogate those snips, but be able to protect that data as well because those tools are extremely valuable for identifying bones that might not be able to get all of the STRs, but you can sequence up some snips and some samples and perhaps manage to make some identifications. But if the family reference samples can't be tested for those because of restrictions, then that's problematic. But if we have some HIPAA protections for that data, then I think that that's valuable.

>> PAUL APPELBAUM: So Vera here is a softball question for you from Bob. What's the evidence that collecting DNA at the border will improve the prosecution of crimes using CODIS?

>> Vera Eidelman: I am not aware of any such evidence. I think it is a great question and one that the government should be asked. But I don't think, I mean, I think's it based on the assumption that immigrants are criminals or more likely to be violent or more likely to have committed past crimes. How someone coming into the country for the first time is likely to be a suspect once within the country, I don't know.

>> PAUL APPELBAUM: Okay, thank you. So maybe one of you wants to take this on. Is there a process that the DNA of the immigrant sponsor can be removed from the database, and then this person also asks, what lab and technology are used for the rapid DNA test? That seems like a separates issue and whether that's certified.

But is there a process with regard to the immigrant sponsor.

>> Vera Eidelman: Sara, do you want to go? I may have introduced this confusion. I think it is not as far as I know, it is not the case that right now DNA is collected

from sponsors. I was talking about the expanded biometrics collection rule that has been proposed by the Trump administration. And I should also say that that rule did recognize that DNA is more private.

It didn't allow for DNA collection in all of the same circumstances as it would have allowed for iris scans for voice recognition, et cetera. But it did allow for it in contexts where I don't think it made sense; for example, an economic sponsor, et cetera. So that is not a live question, but I think it's a very important question to ask should such a rule be considered in the future.

>> PAUL APPELBAUM: And the rule as it was proposed, did it have a provision that would level out removal at some point? No, okay.

>> SARA KATSANIS: No. This is a really good example of why I feel the context matters, because it's important to think about DNA collection for a database separately from DNA testing that requires oversight that the test is used appropriately. And then the retention of the data for both and the retention of the samples for both, these are common.

But how it's being used and where it's going to be placed are very, very different. So collection, so if we are asking sponsors, if sponsors are able to do a DNA test to verify, hey, I'm the biological aunt like I claimed to be of this child, she can come stay with me, since she migrated here on her own and her parents are back in Guatemala, she should be permitted to use her genetic data. But that's a test.

And that test who is overseeing that test? How do we verify that test? Those things need to have some ELSI considerations for how to manage that data and what to do if the test doesn't come up as a genetic link that the person thinks that it might be. So these are the ELSI questions right there which are very different than the ELSI issues with the collection of the DNA data for a criminal database.

>> Vera Eidelman: I think also Sara has raised a couple of times the very important point that there is a test and there's also the sample collection to begin with. And I think to me I have almost the opposite reaction where the sample collection, I mean, I think they are making interesting and true points about the benefits of certain types of collection once you already have the sample.

To me what that makes me think with my civil libertarian brain is oh, my goodness, the government can go back to that sample. Not true?

>> SARA KATSANIS: Yeah, they can't because the ABB lab is holding the sample not the government.

>> Vera Eidelman: Sure. But if they --

>> SARA KATSANIS: Might have a copy of the report, but they won't have the sample. The sample is held by the ABB lab and then the ABB lab has their rules and policies for how long to retain that sample or not.

>> Vera Eidelman: But if we are thinking about, this is a different context which I will recognize, the forensic genetic genealogy investigations thinking about old case. And the lab retained the DNA crime sample. But for a very long time all that was available was the 13STRs. Now we are at 20STRs and now criminal investigators are using that same sample to create snip profiles to then upload to private databases, right.

So it is actually one sample where a variety of differently leveled privacy invasive genetic tests have been done.

>> SARA KATSANIS: Yeah, but that's of an evidence sample, not of a person.

>> Vera Eidelman: Go ahead.

>> SARA KATSANIS: Sorry. Go ahead.

>> Vera Eidelman: So for a CODIS sample, if a sample is taken from an arrestee or an immigrant detainee, that sample is held by a private lab?

>> SARA KATSANIS: No. It's held by the government lab forever.

>> Vera Eidelman: So then we are in agreement for that piece.

>> SARA KATSANIS: Yes. Not forever, I was corrected by CODIS. It's not forever. It's until legally allowed to keep. But indefinitely. Indefinitely. But that's different from a sponsored test. The ABB labs doing tests for context one and these potentially the unaccompanied minors, these are all run through ABB labs. It's also different than the rapid DNA tests where the sampling and testing is done in one machine within two hours, and then what?

The sample's consumed upon use. Do they collect another swab and keep it? That's where we need some policy. Do they keep that test result? Do they keep the data from the test result? That's where we need some policy.

>> PAUL APPELBAUM: So here is another question for you from someone who is interested in what the ACLU has been doing in this area. Could you talk a bit about the collection between the ACLU's work and academic ELSI. It seems that building this connection is important, but I'm not sure how closely these groups tend to interact, forgive that this isn't my area of this expertise, says this person.

>> Vera Eidelman: Thank you for asking that. I fully agree that this is a very important connection to have. Thank you all for inviting me to be here. That's why I'm here in large part. And I agree that not enough of it happens. So I'm really excited to myself make more use of the ELSIHub and learn more as I am already from Sara today and please reach out to me if you are interested in working on this.

I think it's incredibly important and I think there are a lot of ways in which the thinking and the research that you all can do to help us make arguments in court. I mean, I think one of the main things that is hard in the context is the STR argument that we are only looking at junk DNA.



And I think that as in reality almost certainly will expand beyond their STRs already. But I think there are very important scientific arguments to make that will help our legal claims. And I'm also, I learn from knowing what you all are researching. So please reach out to me. I agree it's important to continue the collaboration.

>> PAUL APPELBAUM: So out of both your concerns with the privacy of genetic and other information, we have here an anonymous question. What are the highest priorities for ELSI research on these issues? And how can ELSI research most effectively inform policy?

So for the audience, that's listening and thinking. This is an interesting area. What sort of needs are there? What should we be thinking about doing here? How can we help? What would each of you say? And then I think we are going to move towards wrapping up.

>> SARA KATSANIS: I would say that it's more perspective research is really important. I think because there are these very different contexts and different applications. And some of them have some strong utility and some of them are just downright intrusive and inappropriate to be implemented across the society.

But that's my perspective. And Vera's given her perspective. And understanding the broader perspective of society and being able to break that down because we have these political lines is really hard to dig a little bit deeper into, okay, that's the political nuance. Can we understand better what the actual fear is and what the actual perspective might be about the utility in criminal justice, the utility for national security or terrorism screening, for human trafficking screening.

There are utilities, but what is the risk/benefit ratio? And we can't get to that risk/benefit ratio if we don't understand people's attitudes and perspectives and what they value in terms of the use of this science. Yeah, that's what I think.

>> PAUL APPELBAUM: Thank you. Vera, if you had to ask for one type of data that would be really helpful in that area, what would that be?

>> Vera Eidelman: As Sara said, I come from a clear perspective that I've not hidden. Two. One is just the private nature of whatever type of DNA collection we are talking about. And then I also actually think the network nature is very helpful because I think reminding people that we are not just talking about these scary immigrants populations, but also their family members and ultimately you is a very helpful way to frame this for the agenda that I have.

>> PAUL APPELBAUM: Okay. Well, let me thank you both for an illuminating really fascinating discussion. And thank our audience as well. And let me turn this over to Sandra for some final comments.

>> Sandra Lee: Yes. Thank you very much to Sara, Vera and Paul for this incredibly rich discussion, and to all of you who submitted such great questions. We are going to be able to continue this conversation in our post-forum discussion room which you should be seeing the link posted in the chat box.

And thankfully we have our presenters joining us for that discussion, so I hope to see many of you there. Next week we have our third ELSI conversations on oversight of human and animal chimera research, views of scientists, researchers, oversight committees and the public. And I would also like to invite you to come back in April for our ELSI Friday Forum which is entitled widening the lens, using arts in ELSI research. But thank you to you all for joining us, and I hope you all are safe and well. Bye, bye.