Genomics and Data Sovereignty:  Policy and
Deliberative Approaches for Engaging Indigenous
Communities
ELSI Friday Forum
Friday, May 14, 2021

TotalCaption
Captioned stenographically by Joshua Edwards, RDR, CRR

>> Mildred Cho:  Hi.  While people are joining us, I will just do the introductions and start off our ELSI Friday Forum for today.  I'm Mildred Cho, from the Center for Biomedical Ethics, and I would like to welcome you to our forum on Genomics and Data Sovereignty:  Policy and Deliberative Approaches for Engaging Indigenous Communities.

ELSI Friday Forum is held on the second Friday of every month for an hour at 12:00 noon Eastern Time.  We also have a Zoom room reserved for more informal discussion immediately after the panel for 30 minutes.  So stay tuned for the link that will be posted in the chat box at the end of this session.

As a reminder for those of you joining us for the first time, ELSI Friday Forum is a monthly series of the Center for ELSI Resources and Analysis, or CERA for short.  For those of you who might be new to CERA, it's a multidisciplinary multiinstitutional 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, launched in November.  And we encourage you to access resources there, including the transcript and video of this forum, associated reference material, and an ELSI literature database, a research instrument repository, scholar directory, news and events and much more.  Please also go to the website to sign up for newsletters and events like this one at ELSIHub.org, and get daily updates and news on Twitter, @ELSIHub.

We're pleased to announce the publication of two new additions to our content series, ELSIHub Collections.  Please use the links in the chat to access Realizing the Self-Determination Goals of Indigenous People in Genetics Research which is an essential reading list curated by Vanessa Hiratsuka, that explores the unique ethical and legal dimensions of genomic research with indigenous peoples.

You will also find a link to Game of Bones:  Power, Ethics, and Emerging Technology in Paleogenomics Research curated by Keolu Fox, which examines power and ethics in the field of paleogenomics and proposes technologies to safeguard indigenous remains.

So a few housekeeping tips.  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 time in discussion.  Please use your Q&A button which you will find at the bottom of your screen to ask the panelists questions.

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 and where you can find the links to resources referenced in today's discussion.  If you have any questions, please e-mail info@ELSIHub.org at any time.

I will now introduce Dr. Nanibaa' Garrison who will be moderating this session.  She is associate professor at the University of California Los Angeles where she has appointments in the Institute for Society in Genetics, the Institute for Precision Health, and the Division of General Internal Medicine in Health Services Research.

Dr. Garrison earned her Ph.D. in genetics at Stanford University and completed a postdoctoral fellowship in bioethics at the Stanford Center for Biomedical Ethics and the Center for Integration of Research on Genetics and Ethics.

Dr. Garrison is the recipient of a Career Development Award to explore perspectives of tribal leaders, physicians, scientists, and policymakers on genetic research with tribes.  She is also a member of the Navajo tribe.

Nanibaa', I will hand it over to you.

>> NANIBAA' GARRISON:  Great.  Thank you for that introduction, Mildred.  It's really great to be here.  I first want to start with thanking the organizers for inviting this to this Friday session.  And I'm really excited this topic was chosen, the topics of genomics and data sovereignty was chosen for the ELSI Friday Forum.  I'm joining you from the homelands of the Tongva people.  I'm at UCLA.  And they are the traditional caretakers of the Tovangar.

Our session today will engage our speakers about policy and deliberative approaches for engaging indigenous communities in genomics research and data sovereignty and also governance, thinking about how data is governed in many different ways.  Our speakers today will describe how the crafting of policies and recommendations, carrying out policy analyses and using community-engaged research methods have allowed them to engage indigenous peoples in meaningful discussions about what constitutes ethical, respectful, and relevant research.  I have known both of our speakers for many years, and I'm really excited to see what they've pulled together today, because they've been working in these areas for many different years and taking on different perspectives.

Our first panelist today is Dr. Stephanie Russo Carroll. She is Ahtna-Native Village of Kluti Kaah. She is assistant research professor at the Udall Center for Studies in Public Policy. She's also at the University of Arizona. She's also the associate director and manager of the Tribal Health Program in the Native Nations Institute in the Udall Center and assistant professor in the public health policy and management program in the Zuckerman College of Public Health and American Indian Studies Graduate and Interdisciplinary Program. She's co-director of the Center for Indigenous Environmental Health Research as well at the University of Arizona.

And then we will be joined by our second panelist who is Justin Lund who is a Ph.D. candidate at the Department of Anthropology at the University of Oklahoma. Justin is also a member of the Navajo Nation and is part of the research consortium of tribal partnerships known as CEIGER, which is the Center for Ethics of Indigenous Genomics Research, which has used deliberative methods to engage tribal communities and elicit indigenous perspectives on genomics.

Finally, our speakers and I do not have any conflicts of interest to disclose. With that, I will turn it over to Dr. Carroll.

>> STEPHANIE RUSSO CARROLL: Hi, everyone. Thank you for this conversation today. I'm joining you from the unceded territories of the Tohono and Yoeme people in Tucson, Arizona. I will share work today that comes from my role as the chair of the Global Indigenous Data Alliance as well as the director of the Collaboratory for Indigenous Data Governance.

And through this presentation I will introduce indigenous data sovereignty, the CARE principles for indigenous data governance, and finish with some examples. Next slide, please.

So indigenous peoples data include data generated by indigenous peoples as well as data generated by governments, private sector, other institutions on and about indigenous peoples and their territories. These data broadly information, data, and knowledge in any format that can be digitized. So these data impact indigenous peoples at both the collective and individual levels.

And indigenous peoples' data comprise information and knowledge about the environment and nonhumans which they relate, information about indigenous peoples such as census data, health data, specimens and related data, and information and knowledge about indigenous peoples as collectives including traditional and cultural information, oral histories, and ancestral and clan knowledge.

Next slide, please. Indigenous data sovereignty is the right of indigenous peoples to govern their data from collection and storage to use and reuse. Finding its foundations in inherent sovereignty, only indigenous peoples and nations as rights holders can exercise indigenous data sovereignty. Indigenous data sovereignty is the responsibility and expression of the ways, traditions, and roles that communities have for the care and use of their knowledge.

Using a human rights framework, indigenous data sovereignty leverages tools such as laws, policies and agreements including the U.N. Declaration of the Rights of Indigenous Peoples, nation state recognition of indigenous peoples, treaties and other mechanisms. Indigenous data sovereignty underscores that knowledge belongs to the collective and is fundamental to who we are as indigenous peoples. Next slide.

So data are critical to the exercise of tribal sovereignty. Indigenous peoples require data for governance and self-determined decision-making. At the same time, indigenous nations like many other governmental institutions create and enact data policies and practices that align with their values and knowledge systems. These activities of indigenous data governance are a means of implementing greater indigenous data sovereignty. What we see now is that as indigenous nations rebuild their governance system, they are also reclaiming their data systems. Next slide.

Indigenous nations have various levels of control or possession of their data with high levels of control over their tribal enrollment data and very little control over data that we all have very little control over, so social and corporate data, for instance. Thus, data work for indigenous nations as rights holders requires enhancing relationships with other data stakeholders and experts. Next slide.

In response to the increased generation and use of data and open data, big data, open science and research environments and limited opportunities for indigenous control of benefit, the Global Indigenous Data Appliance, or GIDA, released the CARE Principles for Data Governance which set forth critical considerations for nontribal data creators, stewards, users, and are designed to guide the inclusion of indigenous peoples in data governance and increase their access to data. The CARE principles shift the focus of data governance from consultation to values-based relationships. Next slide.

So here you see the CARE principles and their subprinciples. They are collective benefit, which detail that data ecosystems shall be designed and function in ways that enable indigenous people as collectives to benefit from the data, authority to control which emphasizes the need for those working with data to uphold indigenous people's right to support their interest in data. Responsibility reminds us that those working with indigenous data must center indigenous people's self-determination in the collective benefit and data relationships, and finally ethics, which focuses on using indigenous peoples' ethics to guides decisions on harm, benefits, justice, and future use.

These high-level CARE principles direct those interacting with indigenous data towards regional, for example, the First Nations principles of OCAP or tribal-specific data guidance. Next slide.

The CARE principles bring up people and purpose orientation to data governance which complements the data-centric nature of the popular CARE principles which are findable, accessible, interoperable and reusable.

The CARE principles seek to increase data sharing. Implementation of CARE and CARE principles together should be seen as necessary to allow indigenous peoples to govern, access, and use their data and to share on their own terms. Next slide.

Currently the vast majority of indigenous data ranging from ethnographic material to biological material to Earth observations and so on are neither fair nor careless. These collections can be hard to find. They can be buried in larger collections, research or possessions, corporate data sets. And these data are often mislabeled.

They don't indicate the indigenous peoples who are related to those data or specimens that are not searchable. So indigenous peoples largely are not the rights holders. Thus, these collections of indigenous data are not fair and do not perpetuate indigenous provenance, protocols for use and sharing, or permissions. Next slide, please.

In an international effort led by Dr. Nanibaa' Garrison, we updated a review of how Nation State policies address indigenous concerns for genomics research. Our publication details specifically how the U.S. common rule regulated human subjects research seen here in the column with lots of gray fails to protect tribal collective rights and interests.

For instance, there's no requirements to engage communities for community approval for secondary use of data and specimens, for community approval of research findings before release. And the common rule does not provide sanctions for misuse of samples or data. While disappointing, we know the common rule, which was recently updated, will unlikely change any time soon which demands action in other sectors such as federal, university, and tribal policy and ethics. Next slide, please.

We are really concerned about implementing care on already existing data as well as instituting policies and practices to ensure that the plethora of new data created every day adhered to both. We have opportunities across law which might be slow to uptake within policies such as government policies and institution policies, ethics trainings, but also how we view and ethics full through the data system, for instance, through metadata labels and through infrastructure.

But more tools are needed as well as criteria to assess and evaluate how other institutions are enacting the CARE principles. So the goal is really to create and support indigenous rights to data throughout the data life cycle and across the data ecosystem, and to strengthen the rights by making changes, even minimal changes at first across data actors, research institutions, repositories, publishers, funders, and more. Next I will give two brief examples and then I will be done. Next slide, please.

So in an effort led by Maui Hudson at the University of Waikato, Dr. Nanibaa' Garrison and myself, we addressed how researchers can respect indigenous rights and expectations in order to stimulate greater diversity and inclusion in genomics research by building trust, enhancing accountability and improving equity. To these ends, we include a table with specific actions researchers can take that address indigenous concerns and begin to fill some of the gaps left there by current practices that ignore collective rights and privacy concerns such as protecting personal and community identifiers, and improving publication standards and recognizing community rights and interests. Next slide.

Finally, we see here the Australian Institute of Aboriginal and Torres Straight Islander Research, or AIATSIS, Code of Ethics, which will be mandatory for any research with aboriginal and Torres Straight Islanders in Australia toward the end of this year.

Critically, this Code was co-produced by work from the federal government and indigenous leadership. We see here that it underscores the indigenous people's rights to manage collection, interpretation, and use of their information as well as the ongoing right to ownership, control, and access to research routes, and finally the need to apply FAIR and CARE. Next slide, please. Thank you very much and at this point I will hand over to Justin.

>> JUSTIN LUND: Hello. I'm Justin. I'm a member of the Navajo Nation and also a molecular anthropologist and Ph.D. candidate at the University of Oklahoma where I work as a research scientist for our ELSI center, the Center for Ethics of Indigenous Genomics Research. Next slide, please.

The Center for Ethics of Indigenous Genomics Research is an NHGRI center of excellent in ELSI research based at this University of Oklahoma, but anchored in a collaborative consortium structure between the university and three American Indian Alaska Native research groups.

The structure of CEIGR represents an important shift away from a research model centered on a university towards a model of shared power and respect. Our partner sites, South Central Foundation, is an Alaska native tribal health organization based in Anchorage, Alaska.

The Chickasaw nation is also a partner site as well as the Missouri Breaks Industries Incorporated. They are an American Indian-owned private research organization in South Dakota. Our goals as a consortium are equitable community-driven research that balances local priorities with collective goals, distributes power, and builds capacity. Next slide, please.

Today I will share the deliberation work our consortium completed. This work can be found in these manuscripts. I have highlighted in gray the titles of the manuscripts as well as indicated one that is currently in press. So be sure to look out for that one which describes the cross-site analysis of all three deliberative events. Next slide, please.

In 2018 and 2019, we conducted three deliberation events at each site. Balancing local priorities with collective goals, we decided that the deliberation events -- excuse me. We all decided we did indeed want deliberation events, but our questions were significantly different.

And this was based off of these local priorities. So we had different questions relating to issues around genomics. Our first event at Chickasaw Nation asked our participants to talk about concerns they had with genetic research and biobanking.

Chickasaw Nation was interested in their communities' thoughts on the risks and benefits of genomics research and biobanking.  South Central Foundation was already well into genomics research, so their question interrogated concerns arising from return of results.

Missouri Breaks was working towards establishing a biorepository in a tribal jurisdiction.  And they asked their participants about solutions for expanding research capacity in how to govern genomic data in ways that honor tribal sovereignty.  Each event had between 16 and 20 participants, age ranging from 18 to 75 and ranging in education levels.  Next slide, please.

I keep saying "deliberation," and you might be thinking what is he talking about?  Or maybe he's not using that word the way he thinks he's using it.  But think about it as an extended focus group, but better.  This figure from Ready, et al. describes this process.  There's a similar figure in Hiratsuka, et al.  But it indicates that there was a planning process for us this planning process took about a year, followed by a two-day deliberation event.

And as you can see, these days are defined, Day 1 typically included some group learning while Day 1 as well as Day 2 included all of the deliberation.  And finally the report phase which included checking and dissemination of information back into the communities.  Next slide, please.

Deliberation is not so much a method as it is an approach to engagement.  The theory of practice describes a process of collective decision-making where extended respectful discussion is key.  When this approach is employed in research, it promotes informed community dialogue on complex issues where community views are elevated and ultimately heard.

During an event, any number of various activities could be employed together perspectives.  Here in this picture we are scoring a flip chart activity.  You can kind of get an idea, then, that after this we then use those scores to move the conversation into the areas that the participants indicated were the most important. Next slide, please.

Additionally, we use hypothetical and fictional scenarios to engage the participants. Here is one example. One of my roles in this project was to craft scenarios that were realistic and engaging, but also relevant to the project and to each site's priorities in partnership with their local researchers.

I have highlighted for you words and phrases as examples of our attempts to keep scenarios balanced and nonpartisan. We incorporate issues of insider versus outsider researchers, specific specimen concerns and other issues concerning altruism versus individual benefit. If you would like to see more of these scenarios, they are in the supplemental material of the manuscripts. Next slide, please.

Ultimately, we aim our work to align with the ethical practices of CBPR. This gold standard of research in indigenous communities will promote healthy and beneficial research relationships into the future. And I can't stress enough the importance of the concept of relationships. American Indian and Alaska Natives have good reason to be wary of outside researchers based off decades of harmful practices. Repairing and fostering these relationships is key to moving forward. Next slide, please.

And in conclusion, we found several things that you might already be obvious to you. One, tribal citizens maintain diverse perspectives about genomics research. And this is across sites and even within sites which might be obvious to us. But it's an important thing that we've added to the literature.

The deliberative events provided a dynamic space for participants to engage new information and to interact with one another about the impact of genetics research. And it was a little bit surprising how open our participants were to this and how welcoming they were, as well as grateful that we offered them to this opportunity to share their concerns.

Genetics was viewed as an opportunity that deliberants valued greatly. It might be a misconception that tribal nations and native people are not wanting to participate in genetics, but that's not actually what we found. And lastly, deliberation as an approach to community engagement effectively facilitates dynamic dialogue about genetics research and how community perspectives are shaped by local, political, historical and social factors.

And this was one of the things we were trying to get at with the deliberations, was to see how appropriate this approach was when engaging tribal communities. Next slide. Thank you. Here I have a picture of a core part of our group while there's many others. I would like to thank them, our participants at each of the sites as well as you for listening. Thank you.

>> NANIBAA' GARRISON: Great. Thank you so much for that presentation. I'm very excited to kick off the Q&A discussion. I want to thank both Stephanie Russo Carroll and Justin Lund for those incredibly thought-provoking presentations. We really are in this moment in time where we are seeing indigenous scholars engaging in ideas that challenge the way we think about genetics and engagement all kind of in one space.

So first I would like to ask both of our panelists some questions, and then we will turn it over to the audience. In the meantime, if you do have questions feel free to post them in the chat and we will get through as many of them as we possibly can. But to start, Stephanie, I was wondering if you can elaborate a little bit more on the "A" in the CARE principles. The "A" stands for authority to control. And I'm curious if you could expand on how we balance data for governance with governance of data.

>> STEPHANIE RUSSO CARROLL: Thank you, Nanibaa'. That's a really important question. It's of utmost importance to research to understand that indigenous nations need to have both access to data, so that's the data for governance, as well as be able to assert authority to control or governance over data.

And so it really is an iterative process. As tribes gain more access to data, there's going to be more need for governance of data. And really what this means from a tribal perspective is being able to identify what are the most important data to begin to enrich relationships as Justin was underscoring, to be able to have access to for decision-making within the communities.

What are the data that will answer questions? And then at the same time, how do we care for those data? What are the community norms and expectations for storage of those data, for sharing of those data, for use of those data, what are the protocols around how we -- how that is done?

And so both at the same time, are equally important. And as I said an iterative process of underscoring that. And for those external relationships, in order to gain access, it is very important to understand tribal sovereignty. And the underscoring rights that sit this, that tribes have the right to these data.

And this means that we need to create new systems for sharing, but also really beginning to understand and explore different ways of protecting privacy when we are sharing in small populations, and understand that tribes are not somebody we should be guarding data from, but that we should be building up capacity to protect those data, both internal to tribes and external as researchers and as institutions.

And so that needs to happen in relationship.

>> NANIBAA' GARRISON: Great. Thank you. And that actually is a nice segue to the question that I want to ask Justin. It seems like deliberative methods really seems to be a great way to engage community members in these important conversations around genetics. I was wondering if you could share your perspectives on how the participants responded to the deliberative methods, but also there were probably policy related and governance related discussions that came out that. Can you expand on those two points?

>> JUSTIN LUND: Yeah. So the participants at each site, well first, everybody loves to be heard and listened to. So that's one of the keys of deliberation, is that even for nonnative communications, deliberation is a great way to engage complex topics to come at some sort of consensus.

And traditionally, deliberation can be used to establish policy or to establish recommendations for policy. We specifically were trying not to establish policy recommendations as much as we were trying to elicit our participants' perspectives.

As far as how they responded, you know, at first, we're all a little wary the research and we can be a little bit uncomfortable and kind of dip our toes into the situation. And having two days with participants, it allows them all of that space. It allows them the space to get comfortable with us, and then it allows them the space to be comfortable speaking up and speaking to each other. And so as a practice, this worked out really well.

And I can only imagine it much of the time works out really well because of the way people like to be heard and to hear people. In tribal communities specifically, though, I always had high hope for these deliberation projects, because as some of us might know that community speaking and coming together for consensus decision-making is an indigenous way of doing things.

And so our hope was that this nonindigenous way of doing something might lend to a friendly way of building relationships between research and indigenous people. And it did. As far as your second question about how this might shape policy, you know, these as I said in the reporting phase, we reported back to each community. And one of our communities, the report was forwarded onto the tribal governance to discuss more about data sovereignty and governance of data that they were starting to produce.

So it can be used as a very good tool. It can be and has been. With our other two sites, they use it as a tool to look forward a little less looking at policy, but a little more looking towards what their capacity and what they can and want to do.

>> NANIBAA' GARRISON: Great, Justin. And although I still had some questions for the two of you, I do see a question in the chat where somebody asked Justin, weren't you trying to translate the deliberations into policy recommendations?

>> JUSTIN LUND: Not specifically, not specifically. And often that was one of the things that we discussed in outlining what our deliberations were going to be about. If you read the power sharing paper that I provided to you, we talk a little bit about the challenges that we had in arriving to a collective goal. We all are at different places.

The university has an agenda, not an agenda. The university has motives for research. Each tribal nation is in a different place. So with these policy recommendations, it seemed a little bit too aggressive for our tribal partners, and they didn't really feel comfortable with that.

And it's all about building this relationship. And so we discussed and had meetings about what everybody was comfortable with. And we decided not to go towards policy recommendations. More to just elaborate on perspectives of our indigenous partners, and to contribute that to the scientific literature.

>> NANIBAA' GARRISON: Great. Thank you. And in Dr. Carroll's presentation, she has a slide that talked about how indigenous data governance can be supported through multiple different avenues, one of them being ELSI and ethics. I was wondering if both of you can comment on how the ELSI community in particular can help to support indigenous data governance.

What are some areas that we need to focus on or how can we move the work forward that we are all working on and translate it into ways that can really help to support data governance? Stephanie, maybe I will put you on the spot first.

>> STEPHANIE RUSSO CARROLL: I can go first.

>> NANIBAA' GARRISON: From your slide.

>> STEPHANIE RUSSO CARROLL: I will go first. And I will point everybody back to that paper, the Hudson et al. paper that really talks about building trust, enhancing accountability, and improving equity. We detail a number of tools and mechanisms of moving forward, but importantly there are three components that must be understood.

So the ELSI community can first begin to understand and put into practice how building trust relies on and emerges through recognizing indigenous rights and interests, and understanding that the base of that is support for and creating practices around indigenous sovereignty and self-determination.

And so that can look like how you have these relationships with tribes or it can be reflected in semilegal documents, so an MOU or a data sharing agreement that puts that into practice.

And then enhancing accountability arises through maintaining transparency particularly around the provenance of data.  So this pushes us to try to figure out how do you include provenance, attribution as baseline elements of metadata for your samples and your data?  Who is in relation to these samples?

And then you begin to understand why that becomes important to understand what are the protocols around these data?  How do we care for those data?  What are the uses they have been permissioned for?  Who do I talk about using them in the future?  And finally improving equity happens when indigenous communities benefit from data and data use.

And this is on their own terms.  And so this can be anything from publication and having relationships around publication, so those publications are done with indigenous communities but under permission of and so forth.  It can also be done through research or commercialization activities.

And understanding where there might be interest in commercializing and where there's clear and set boundaries around commercialization and figuring out what those benefits are.  And those benefits need to be decided in consultation with and at the direction of those communities.

Justin?

>> JUSTIN LUND:  I completely agree with everything that Stephanie has said.  The only thing that I will add because I have been thinking about it a lot lately that kind of encompasses that sentiment is this idea of power sharing.  And not just sharing, but giving up power.

That's an important factor, I think, that the ELSI community and all researchers can do when doing research in Indian country.  It brings to mind something I ask myself is as researchers if we don't want to share or give up power, we really have to ask ourself why that is.

And the last thing that I will say about this because I say it everywhere I go is that natives and indigenous people want to be telling their own stories.  For far too long, the stories of indigenous people have been told by others.

So part of finding that equity is in allowing people to tell their own stories and to define themselves, really.

>> NANIBAA' GARRISON:  This is fantastic.  Thank you so much.  I think what I will do now is open it up to audience questions.  I first want to say that I did have a raised hand, so I am going to call on one panelist, and then I will read off some additional questions that are coming through the Q&A.

So first I am going to ask someone to ask her questions.  Can you unmute and say your question?  You might need to raise your hand in order for us to unmute you.  Are we able to do that?  Okay.  We might be dealing with some technical challenges here.  But it looks like she has a few questions here.

One is it looks like there's not an unmute button for the guests.  Okay, so she does have a few questions here.  So regarding deliberations, Justin, how were participants in the deliberation selected and recruited?  And she also has a follow-up question for Dr. Carroll.  Can you explain the way you used the terms rightsholders and ownership?  How that contrasts with the concepts of ownership?

So Justin, I will have you respond first.

>> JUSTIN LUND:  At each of the sites and it's reflected in the manuscripts that I've offered, the recruitment was a little bit different.  And so I don't

want to speak too much on that, but just because they were done so differently at each of the three sites and it's one of the things that each of the sites prides themselves on as well is their ability to recruit a representative sample for the work that -- for the questions that they had and the work that they wanted us to do.

But I would appreciate if you have any questions more about that after referring to those manuscripts, if you could e-mail me or anything like that.

>> NANIBAA' GARRISON: Great, thank you. And Dr. Carroll, can you explain a little bit more about how you use the term rightsholders?

>> STEPHANIE RUSSO CARROLL: Sure.

>> NANIBAA' GARRISON: And ownership.

>> STEPHANIE RUSSO CARROLL: So I will back up a little bit and underscore that within the indigenous data sovereignty movement, we really used rightsholders to indicate indigenous peoples who underscored and the Declaration of the Rights of Indigenous People have inherent sovereignty whether or not that's recognized by the nation states in which they are currently located.

And that's really important because even UNDRIP doesn't recognize sovereignty within a European context for indigenous peoples who might be there. So we need to understand there are political boundaries that try to restrict sovereignty and self-determination.

And so those are very important concepts to understand. And so within the U.S. context here, we have 574 federally recognized tribes, about 60, maybe, state recognized tribes. So it is easy to understand or easier to understand who might be the authority to go to of that tribe to receive permission for research, right, to have research reviewed.

It is much more difficult to figure out who the appropriate entities are to engage in other contexts where you might not have federally recognized tribes. But it is important to understand that the rights are still there. And this also underscores the importance that sometimes the beliefs around data sharing and the expectations around data sharing are not written.

They are verbal, and so those rights are not diminished if they are not written. So ownership has been a tricky term. We shied away from using that with indigenous data sovereignty context originally because indigenous peoples like all of us as individuals can't own all of our data.

And our rights around our data vary as set forth by Western legal systems. But indigenous rights are there, and they are enumerated in a number of different documents about how indigenous peoples have relations to their data, their specimens, and the expectations are set forth by those communities.

Ownership is actually kind of in transition in a concept of, you know, how do we relate to it as indigenous peoples? I think because you are hearing more and more indigenous voices, because it's not a concept that is indigenous in terms of how we relate to our data.

And we have to understand in different communities the interpretation and the use of that from a non-Western legal perspective is going to be different. And those need to be understood from those community contexts. But it is extremely important to understand that indigenous peoples, whether or not the nation state recognizes them, retain self-determination and sovereignty.

And those expressions of such need to be determined by those communities.

>> NANIBAA' GARRISON: Great. Thank you so much. We do also have a question in the Q&A from Dr. Bob and multiple people are very interested in

this question as well as I can see. He asks, can you give us some pointers about how to deal with the problem of historically exclusion? I'm thinking in particular about the absence of data in multiple data sets and others that have practical effects on interpreting genomic variance. Those are unfetterred open fair access and thus don't align with the CARE principles. How do we achieve inclusion while respecting CARE?

>> STEPHANIE RUSSO CARROLL: This is a fantastic question. And it really gets at the two different types of data, right. So there's data that's already sitting within those holdings, and then there's data being created every day that are going to be added into those. So we need two complementary approaches. We need to be able to change policies moving forward for how data are created and collected, and then deposited into these different data sets.

And then we need to be able to understand how might we might have backwards and be able to find these data that are indigenous data? And so there's a few ways and tactics to do that. The first is obviously these data sets are repositories. We need to understand what they are holding. They need to begin to change their policies and procedures. So they might, for instance, set forth and put out an ethics statement.

I point you toward variant bio, who has an ethics statement. There's very few of these public ethics statements around data, particularly indigenous data yet. But there's another method that's been used, particularly within collections management that's put in a notice on. So cultural institutions notices which can be found at local context.org. And these signal that the holders of these data understand that there are relationships that need to be made and changes that need to be made to the data. Very simple statements, but huge ethical terms and saying that we understand that these might not all have been collected or stored or used or even have relationships in ways that in the future we want to change.

And then you begin to do things like change the field, right, adding fields, adding metadata fields to your data set so that you can include provenance. We have an effort right now through the IEEE, which is the Institute for Electric and Electronic Engineers. I'm the working group chair for that to create a provenance standard for that for indigenous data.

So creating fields for the information that needs to be there. And then it's also creating relationships. I always suggest that wherever these data are, that you at least have a relationship with the indigenous peoples in your area and whose land you are on. That's the way to build up an accountability and understanding.

They may not be represented in your data set, but they can give you guidance on expectations and moving forward. And these relationships are extremely important. Many institutions, universities have some of these relationships that you can start moving forward through. And finally I will just say that that, you know, another way to move backwards and forwards through this is to grow those relationships with indigenous researchers and students and others in ways that support them as scientists and promote them as scientists, but also as experts in being able to utilize multiple ways of knowing to answer these questions.

And so I often see especially in health sciences while there's many of us who are indigenous scientists in the field, we are not part of the process moving forward of sitting at the table to understand how we need to point back to communities, have relationships with communities, and pay for our activities.

I'm often asked, I know others are often asked to give free labor. How do we build this into the processes of how we build up and change these data sets and repositories?

>> NANIBAA' GARRISON: Great. Thank you so much for that response. It's very important to think about all these principles in tandem with each other, not in isolation, but working complementary with each other.

I also would like to ask this question in the chat, in the Q&A. What implications do your findings or your work have for the informed consent process for research recruitment in indigenous communities? Justin, I was wondering if you would like to take a crack at that answer first. Thank you.

>> JUSTIN LUND: Of course. That's a great question. And actually consent came up at all three sites. And it was something we had expected. And we, we, the conversation seemed to revolve on having dynamic forms of consent, and that the current consent process is not adequate for community-level data.

So going forward, these conversations are going to continue. I believe we have some talks with some other tribal nations to discuss consent practices and what policies or what recommendations those participants might have towards changing or making them better.

>> NANIBAA' GARRISON: Great, thank you. And I see another question by Julia Brown who asks, while it is important to build transparency and trust in the collection, storage and use of samples today and also in the future, I'm wondering about biospecimen minutes that were previously collected without appropriate consent.

So this is a large, a huge issue in indigenous communities. She goes on to say in Australia, there have been recent and extensive efforts to consult family members in indigenous communities about the use of DNA collected in the 1960s. What about in the U.S.? Do deliberations include discussions about legacy samples?

>> JUSTIN LUND: We did discuss, we did discuss samples that are currently collected. And the perceptions on how to handle those samples varied. One of the things that Stephanie just kind of touched on that these things exist. These data sets exist. In a paper that I recently submitted, one of the things that I talk about is colonial knowledge. It's all this knowledge that we have a ton of. Hundreds of years of.

And that's not a bad thing. The authors that I cite for this work Woke and Wagner, I believe, they talk about colonial as being a good starting point that if we start to recognize this work as not always a negative but as a starting point for fixing relationships, for understanding the data, for interrogating the data, there are ways of getting information out of that data that aren't colonial when viewed in appropriate ways.

I do recommend that paper by Roke and Wagner on colonial knowledge. It's very enlightening.

>> NANIBAA' GARRISON: And Stephanie, would you like to add to that too?

>> STEPHANIE RUSSO CARROLL: Yeah.

>> NANIBAA' GARRISON:

(Laughter)

>> STEPHANIE RUSSO CARROLL: You can move on.

>> NANIBAA' GARRISON: We can spend all day talking about this, definitely. Okay. So there's a question from Emerald who says do you have recommendations for genetic counselors in the consenting process and how to work to advocate in the genetic counseling field? As we know genetic counselors are

majority white non-Hispanic women.

And just recognizing that positionality and how it affects what is appropriate within that role?

>> STEPHANIE RUSSO CARROLL: So I looked at this question and I thought Dr. Garrison would be the most appropriate personal to answer this question. But I will likely touch on what Justin answered and this question as well, which is I think that we really need to move and understand basic educational needs of the people who are consenting.

The vast majority of us who have gone through mainstream education systems within the U.S. and in other places do not have any education on indigenous peoples in general, let alone anything around genetics and data sovereignty and so forth.

And so I do think there's a baseline training need for ethics around this. I also think that we need to understand when and how we need dual layers of consenting. And that means both individual consenting as well as collective consent, so tribal consent for activities.

And when it's appropriate that those are necessary, both to have them and when we might have solely individual consent necessary.

>> NANIBAA' GARRISON: Great. Thank you. I think we can move on. But I think attending webinars like this and just hearing multiple perspectives from a very diverse group of people is another way to continue to expand our knowledge about ways of engaging people from multiple different backgrounds in these important discussions.

I would also, I'm really curious about this question by Steve who is a cloud architect and is often challenged by legal complexities with regard to governance and access to data in the context of public consumer clouds like Amazon Web Services. How have indigenous communities managed data governance and authority with respect to consumer cloud offerings? Stephanie, would you like to try that question?

>> STEPHANIE RUSSO CARROLL: I can try that question. So you know, I don't have flat-out examples of the challenges around that. We still have significant infrastructure challenges within indigenous communities. Many do not have broadband and they don't have the capacity to be actually engaging regularly in cloud services.

But what we have seen is, for instance, at Kahnawà:ke Mohawk, is they have created their own data systems and servers which is one way to go.

I will tell an important story which is in New Zealand as they moved toward their integrated data infrastructure to kind of knit and link all of their data sources in the way that you are linked from birth, for instance, in a Scandinavian country, as they move towards that, the New Zealand government was going to off shore all of their data and use these servers offshore.

And the Maori elite tribal leaders forum came to them and said no way, you cannot do that. You need to think of the implications of storing all of our data as indigenous peoples, but all of our country's data on another server that is outside of our jurisdiction as these servers currently are.

So there will soon be a paper out that describes that process, but New Zealand is actually going to store their data within their own country at the behest of tribes there because of these critical considerations. And so you do see some movement towards indigenous, I would say design and innovation, really pushing forward and making people think hard about these.

But I know from a local community context, this is an issue and people choose different servers. A lot of times I see local communities choosing servers in for instance Europe, right. So some of those Amazon servers that are in Europe because of the GDPR.

>> NANIBAA' GARRISON: Great. Thank you. Justin, would you like to add to that question?

>> JUSTIN LUND: Yeah. As far as jurisdiction, jurisdiction is incredibly important. And it's one of the things that we talked about as a consortium, the need to put these data within tribal jurisdiction. And one of the areas in which we can watch in the future is with the Native Biobank Consortium in South Dakota as they are setting up a biorepository on indigenous land with this intent in mind.

>> NANIBAA' GARRISON: Great. Thank you. I think that could be a whole different webinar in itself. Great question. We also have a question and this is directed more towards Justin. I notice that deliberation from indigenous communities are not often cited in papers on deliberations to nonnative communities potentially because researchers believe indigenous peoples have perspectives that are distinct from nonnative people. Who learnings from your work do you think are relevant to deliberations with other marginalized groups or any participant group?

>> JUSTIN LUND: That's a really good question. I think that while we all have similar -- we all live in the same world and we all have perspectives on these complex issues. I think that's the key with deliberation is that in other marginalized groups, it works in a similar way to get at these perspectives that we all have on complex issues.

Whether we've gone to get a Ph.D. or not, all of us have some idea about how we feel about genetics research. And using deliberation to get at these ideas in any marginalized community seems like an appropriate way to elicit these perspectives that might be lost otherwise.

>> NANIBAA' GARRISON: Great, thank you. I think we have time for one more question, very briefly. One person is asking about direct-to-consumer genetic testing companies and whether indigenous people should be concerned about underrepresentation in that type of research or how data sovereignty might be lost in that context.

>> JUSTIN LUND: Yes.

(Laughter)

>> JUSTIN LUND: It is a concern. You know, we are bound as researchers at universities, we are bound by certain policies of ethics. And while these companies do have policies of ethics, their practices remain a black box to us. And so that's one issue.

The other issue is that Native American identity is tied to land and ideas of sovereignty. So when companies are creating and disassembling that kind of identity in the population, it becomes an extreme concern for how that might impact the sovereignty of these individual nations that exist in our country.

It's something that we are all keeping a close eye on and we talk about frequently.

>> NANIBAA' GARRISON: Great. Thank you with that. I don't think that these conversations will end any time soon. We will continue to think about these frequently and have these conversations frequently. But I want to thank both Stephanie Russo Carroll and Justin Lund for their participation in this discussion today.

Thank you so much for entertaining all of the audience questions and for a very thought provoking discussion. I want to turn it back over to Mildred Cho to wrap up the event and thank you all so much for attending.

>> Mildred Cho: Thanks. And before you guys sign off, please note that we have another webinar to continue these discussions where you will not be on mute. We are losing Dr. Carroll who has another event, but we will -- (technical difficulties) -- a bit more extending this discussion. And thank you for joining today. We hope to see you in June for our next ELSI Friday Forum, Ethical Challenges in Novel Gene Therapies for Sickle Cell Disease. Our panelists will be Dr. Liza Johnson and Dr. Melissa Creary, moderated by Dr. Pilar Ossorio.

We also ask you complete the ELSI Friday Forum survey which ensures our programming addresses issues that are of interest to you. And hope to see you in the post-forum discussion room using the link in the chat. Thank you so much to all of our panelists.

>> NANIBAA' GARRISON: Thank you.