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welcome to ELSIconversations hosted by the Center for ELSI.

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Resources and analysis, staffed by teams at Stanford and Columbia Universities. I'm.

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Mildred Cho and I’m pleased to moderate our conversation today.

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These conversations are designed to foster active engagement. So, our 3 discussants today have provided recorded videos on the ELSI.

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Hub website that I hope you had a chance to see.

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But they will be doing very brief recaps right now. and that will serve as the basis for our discussion today, and we'll refer you to ELSI.

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Help for speaker information rather than me, giving them lengthy introductions.

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So since this is a discussion, we encourage you to turn your cameras on your videos.

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And after the recaps all moderated discussion, so feel free to use the hand, raise feature then, or the chat at any time.

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And if anybody needs any support, send direct message in the chat to Dounya or email info at ELSI.

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Hub dot org. We also would like to encourage all of you to submit ideas for future ELSI.

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Conversations. and I will now hand things over to Alice Popejoy, who actually proposed this series.

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And she'll introduce it today as well as today's session.

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It's a series of 3 conversations and I hope. This conversation today will lay the groundwork for a kind of sustained discussion about the ecosystem of diverse stakeholders with interest in the

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use of race ethnicity and ancestry and genetics and genomics.

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So I will hand it over to you else thank you so much, Mildred and I just want to express my gratitude to ELSIhub for hosting us for this conversation series, and we're gonna kick it off

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today with this first session topic which is shedding light on the use of population descriptors in clinical genetics. so I’ll give you a brief recap, and then we'll get recaps from

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our other speakers, Hannah Wand and Gillian Hooker, and then

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We will open it up for discussion with the whole group. So as many of you may be aware, there is a lot going on around this topic of race ethnicity and ancestry as population descriptors and the national academies currently

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has a committee can be to look at this in genomics research.

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But this this work in clinical genetics is somewhat outside the scope of what the national academies is working on, and it's something that we've been looking at in the ancestry and diversity working group of

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Clinton since 2,017. So, this is the current membership, and some former members picture here as well.

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I just want to acknowledge all the hard work and the dedication of many of these folks in Clinton and in the working group who just joined the working group without evening part of Clinton because this is something that that

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they've focused on and we're really grateful to have everyone participating from so many different disciplines from history and bioethics.

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Social science, counselors, clinical geneticists, population and statistical geneticists, and it's really, through this richest of interdisciplinary collaboration and discussion that we've been able to dig

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into these topics, and our charge has been to identify recommendations or guidelines for the use of race, ethnicity, and ancestry in clinical general genetics, and of course, this is part

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of a much larger effort of the clinical, genome.

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Resource. Clinton. the ancestry and diversity working group is just one of many working groups. and You can see many of the people who are involved in the leadership at here.

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So when our work first started in 2,017, you know, we thought it would be sort of easy to just do literature search, look for all the evidence, and then come up with some evidence based recommendations for race ethnicity,

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an history in clinical genetics but it wasn't that easy, because pretty quickly I learned that there aren't even really standard definitions for race ethnicity and ancestry which makes a conversation about how to use those

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things somewhat challenging. So, and there still are no standard definitions for these terms.

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However. there have been several efforts to define them for various purposes, and of course you know there are scholars who's life-work

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Work is dedicated to these nuanced questions, so I don't pretend to be an expert in that.

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But we did convene a group of the psychiatric Genetics consortium

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Putting out a paper on GWOS and diverse populations.

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And the definitions that we came up with were that race are really linked to social power dynamics that these races, really inextricable from racism ethnicity is used interchangeably with race

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and can be used in sort of all sorts of ways whether it's more cultural or social, or even potentially ancestral and ancestry is really in this context, about looking at people's genotype data and comparing it

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to reference populations and getting an estimate of somebody's ancestry.

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So, if you watch the this presentations in advance, this is all just recap for you.

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But this is a for some folks who may not have joined in the United States.

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We use a race and ethnicity on almost everything.

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Government related and informs we have these categories that are given to us by the office management and budget.

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And these are used throughout biomedical research and they're in our electronic medical records, and of course they're on clinical genetics laboratory test requisition forms. So that's what

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we're going to be talking about today. is a sort of fluidity of these terms, and these categories that we use, and how they're used in clinical lab reposition.

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Forms. So you maybe saw this slide or seen it before. You see my talks.

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We looked initially at requisition. forms and found that the categories were all over the place, but that the different categories that we use are certainly not.

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They're not streamlined at all across laboratory, So this is something that we wanted to look deeper into, and that is really the motivation for today's the session, and the series we

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partnered with Oh, sorry. and within the working group. we we really wanted to go further than this? So we looked at the survey, and I don't have slides on that.

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Now you can go back and watch the video if you didn't see it.

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But really we need to work towards broad consensus on the user race and this and ancestry that's really our goal.

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We found that more than 65% of our survey respondents agree that this is important, and we've been working with ACMG and liaisons from NSGC.

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And ASHG to really figure out what is going to be the best configuration of guidelines.

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And how we can work together to create those guidelines for the community.

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And there is an official guideline development process through the American College of Medical Genetics and Genomics, which starts with a systematic evidence review, and then a guideline Board.

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Review. So we are in conversations with ACMG about this, and we hope to actually have a formal process that will kick off.

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And much of what we talk about here will serve as evidence or information that we can use to guide that process.

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So some of our motivating questions to generate evidence-based guidelines are, How is information on clinical lab test?

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Requisition forms used in clinical genetics.

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Practice. And then what is the most important information for clinical genetics?

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Professionals to do their jobs. Is this information always necessary?

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If not, when is it critical versus one? Is it extraneous, and one Is it potentially harmful?

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And maybe one is it potentially harmful not to use them?

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And if changes to these forms were to be recommended, what are the considerations that need to be made to implement those changes?

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What are the barriers and opportunities? so in partnership with ELSI.

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How we have designed these ELSIconversations sessions to address each of those motivating questions. So today we're going to be talking about shedding light on the use of population descriptors and clinical genetics

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that's understanding the context for these terms and how they are used on clinical lab reposition forms the next in our series is called Utility of population descriptors and clinical genetics.

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So our goal within the second session, which is going to be on May the sixth, is to distill the most relevant information among population descriptors that serve a purpose in clinical genetics. curation pipeline and other work in the

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field, and finally on May twentieth we will be hearing from folks talking about the considerations that are necessary to change clinical forms at scale.

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So if you're looking to revise the demographic representation on clinical acquisition, forms what are some of the challenges? and what are the opportunities?

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So again today. this is our topic. we're just going to understand the context for race in the city, and industry on clinical lab requisition forms, and I'm going to hand it over now to Jillian who's going

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to give us a little bit more insight into what kind of lab reposition. Forms are in the context of the field Hi, everyone.

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It's really a pleasure to be here today. and I’m very excited to be a part of this conversation for further introduction. I currently serve as the chief scientific officer of concert genetics a health it company I’ll give you a little bit more

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background on in a moment. I'm also an adjunct associate professor at Vanderbilt University Medical Center, and I am a member of the Clinton ancestry and diversity working group.

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So what we've been working on a concert relevant to this conversation is really building infrastructure to enable efficient ordering and payment of genetic testing and looking at each part of the genetic test order

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process, understanding the standards that need to be applied at each part.

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The way that different stakeholders, the folks are ordering tests on behalf of their patients.

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The labs that fulfill the test. the payers that pay for the test, understanding what the information needs are of each party at each step, and building an engineering both in a software way.

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In a process way to a process that flows better than it does today.

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Today. it's a very fragmented process and a lot of information is gained in lost at each step.

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But it gives us a really unique perspective on the way that information is collected in those in various steps of the process, and specifically relevant to this discussion around requisition, forms, we as a part of a number of data assets we have

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to enable ordering of genetic testing, have built a repository of requisition forms which we actually use in our software to collect information from folks who are ordering tests.

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And then auto populate those requisition forms to send off with a test.

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We got involved in a collaboration, our team at concert.

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We had an intern at the time, was now practicing genetic counselor, Catherine Anderson.

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We started working with Alice and Julia Gimmer, not mail on a project to analyze the requisition forms that we had in our repository, to look to see how they were asking about race

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ethnicity and ancestry. and we also pulled in other requisition forms that are used internationally in other countries for the ordering of tests.

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And so these are the forms that collect the patient information.

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They often collect insurance information, they document, which test is being ordered, and then very frequently, very commonly, in the United States.

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They have questions about race, ethnicity, and or ancestry.

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And what we saw in our analysis is that in the United States they are more likely to have these questions then, and requisition forms that are used abroad.

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They are more likely to ask about race and they're more likely to use discrete categories to do that.

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So there are really some striking differences. That paper is soon to be submitted, and I think you may be hearing more about it.

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Other parts of the discussions today. I think that the more broadly perspective I can bring to this conversation is thinking about how this information does get used systemically and by different stakeholders, and in a part of my introductory talk I talked

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about policies and billing methodologies that invoke race or ethnicity in in their use, or even in their recommendations.

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So you'll see with an nccn you'll see within pay your policies, and even within cpt codes the procedural billing codes for tests you'll see references to most

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commonly Ashkenazi, Jewish ancestry,

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And indicating particular instances in which other folks may have coverage for tests or codes, may be appropriate for folks in that way, and so really calls to light sort of the systemic ripples of the way

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that requisition forms of the information collected clinically has really been institutionalized in the Us.

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Health care system in such a way that it is truly systemic.

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And that as a part of changing guidelines and moving in this direction, I think we need to consider all of those various incentives and institutionalized practices that will be impacted.

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Thank you very much, and I’m looking forward to the conversation

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And I will go next I’m gonna want I'm a jet counselor and preventive cardiology, and I’m also the director for a pilot initiative at Stanford healthcare to develop what

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I call precision, public health, infrastructure.

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So my recording then discusses how r a is collected and used in clinical practice with 1 one provider encounters, as well as more of a population health perspective from a healthcare system's point so i'm going

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to recap the table from that recording can see it.

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Can everyone see this slide? Okay. Great So just really quickly walking through

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I thought it would be helpful for a non-clinical audience to really understand how race ethnicity and ancestry comes up in a clinical genetics encounter.

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It is kind of bridging with the topic for the next session, but just really quickly walking through, and I did purposely want to point out.

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I combined Ra here on purpose. Alice did a nice job of distilling how from a research perspective in genetics we see these as different concepts on the clinical side, though we are never you know calculating so much

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genetic ancestry we're often extrapolating it from race and ethnicity.

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I'm So on the clinical perspective these are often merged concepts, and i'd say from the patient perspective

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That also tends to be true. So in this first room here you have the initial and take into a healthcare system, and typically, race and ethnicity are used.

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Alice showed the Lmb. descriptors that is typical for all new patients in a hospital system.

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At this point of care. Nothing specific to genetics but it may be used by the hospital, or that genetics clinic to really assess he was accessing care absolutely more of a population health metric when you're just you

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know, ingesting a new patient into the system. the second, or then that is where you really get into genetics practice.

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So at the initial intake and a genetics clinic.

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Raa is a major point of the risk assessment.

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Race is a risk factor, as we all know it's a social determinant of health.

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If you're seeing complex diseases you want to be aware of someone's race.

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But ancestry again realizing these are completed terms that's usually used to, if it's indicative of an increase risk, because there might be a founder population with a certain condition.

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We use it for things like carrier screening.

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You know there are debates on how useful that is in practice.

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But it does come up in that initial intake. ancestry.

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Here again collective myself, report in a way that largely reinforces someone's an individual's conceptualization of their race and ethnicity.

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This used to be done by genetic counselors or geneticists.

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It is, though moving towards software or an accounting assistance.

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So I would say, before we can ask really clear questions of what we meant.

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But now it's kind of up to the patient to interpret what we mean when we're asking these questions.

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So I do want to know that that's the very new kind of change in practice.

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But depending on who's asking you do tend to get more rich information than just a demographic student here. So people will often disclose kind of their country of origin, where their families, from from whatever way that they conceptualize what we're

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asking about so you'll see often in like pedigrees and things like that that they'll have like someone might be from China or Mexico.

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It tends to be very geographically grounded for a lot of people.

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And then in Rose 3 and 4. the actual risk assessment via provider.

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If it's you know with providers and doing number 2, and sometimes these things are in conjunction with one another.

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But here is where you might revisit an history I would say it's largely the same as that intake.

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But again there might be a need to clarify

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And then, as Julian mentioned with test forms and Alice showed with that picture, When you, if someone decides to go through with genetic testing, you do need to fill someone's answer, history is often required in the test forms what they have is

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options and structured ways may not match with the conversation unless with the patient.

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So you may need to go back, but I also want to note that a lot of providers make assumptions about race based on someone's appearance, because it's often physically assigned to people so it's not

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always the case that people are going back and asking people they might fill in someone's race or ethnicity based on someone's physical appearance just for the purposes of filling out a test for that is not something

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you'll see reflected in literature, but does happen in real practice.

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I had one other slide from my presentation. I mentioned that people have very non genetic concepts of an industry. and just wanted to have this as an example of these are things that do come up in conversations with patients when you start to

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ask them about their family or where they're from or how they think about heritability of conditions, or just heritability of genetics.

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So I think this is probably not surprising to people, but I think it ties in nicely with the next talk that there are other reasons that we talk about raising clinical encounters that don't have to do a test

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interpretation and ordering. and these are really things to be mindful of, as we talk about how we shift practice to match more like modern uses.

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And conceptualizations of these terms it's all end there hopefully Hi R.

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Reset it right? and we can discuss now. Yes, thank you so much.

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Hannah and to kick us off on our discussion.

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I am going to ask the audience a few questions. if you would indulge us just to get a sense of where everyone is in your own thinking.

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Since we are talking about population descriptors on these test requisition forms.

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What words come to mind when you think of a population?

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And in order to answer this question, you can text my last name, Pope Joy to this phone number listed here 747, 4, 4, 4, 3, 5, 4, 8, or you can go to pull up dot com slash, pope, joy and

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give your answers there. so we'll give folks just a minute to do that.

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And, by the way, once you text if you are using your cell phone, if you text popejoy, to that number, you'll be logged into the full everywhere session for the whole session. and So you won't need to do

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that again. If you want to answer the next couple of questions us I don't know if it's just me I can't see a number.

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Can you repeat it open and check. Oh, it 7 you can't see it on the screen.

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I I cannot No. I guess the results Okay, let me change the sharing.

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How's that same screen right now? Hmm okay, let me try this again.

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I don't know why do you wanna just put it in the chat, sure although it should, if you wanna repeat it. I can type all you now.

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It's gone away for me

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Let's see if I can try this so how about can you get me

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Are you seeing those results coming in Yep: Okay, great I love doing these activities in different settings?

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They're often very similar sets of words but sometimes they're different

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I think we often take for granted this word population. It gets used a lot.

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In in research, in clinical care, and colloquial settings, conversations, and I don't think we really appreciate

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How varied a term this can be. group is sort of winning out.

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But we have also geography, background, community identity, location, ancestry, characteristic origin.

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To some of these that i'm seeing this is really rich and thank you so much.

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So you can continue to text in your words.

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Just for seconds. Okay. So the next question I have for you is, what does the word race mean to you?

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And, by the way, if you are on your computer for this I believe that you can actually vote on a response that somebody else has already entered.

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So it'll just up the counts sort of vote

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Alright, We're seeing social construct in at the top 7 votes and skin color Discrimination identity, Appearance Categories Russian Baseless Political group Genetic origin, Oppression proxy outdated Idea of Dividing

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humans, social, belonging, fascinating. Thank you so much.

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Alright. now, how about ethnicity?

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All the culture, cultural background shared culture, origin, language, and religion categories. Hispanic.

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Yes, in the Us. it's just Hispanic, the official ethnicity, cultural, upbringing, social identity country of origin, language, background, cultural history actually looks like we have some consensus.

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On this one. Thank you so much. alright. So this is the last one.

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How about ancestry? What does that mean to you?

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3 personally and professionally, a little bit

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Okay, So we're seeing genetics we've been in at the top with lineage geographic origin, place of origin, family history, awesome lineage relatedness shared genes genetic ancestry, genetically determined and

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linked to continental origin. Where are my family? is from?

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Where your N star, great grandparents lived alright, so really about relationships, genetics, origins, alright.

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And finally I did say this is the last one but there's one more.

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This one Oops. We want to know how important you think it is to have population descriptors like race admissions, ancestry on clinical lab test requisition forms

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Yeah,

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I want to go as much data as we can on this one.

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So maybe, Melchron, if you wanted to start the discussion, we can let the responses continue to roll in here.

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This is the last interactive question I have for you thank you against so much for participating in our in our work.

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We're gathering evidence from you and then hopefully in our discussion.

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We'll hear more from you about your perspectives, of course, questions you have. but also, if you have very strong feelings or opinions or experience with this, we want to know from you this is all about the test requisition form and

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clinical genetics, and and How we're using ancestry or other population.

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Descriptors are are used on those forms from those forms, etc.

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So thank you so much. Thank you Thank you all and I hope everyone here, if they haven't had a chance to see the recorded videos, please go and check those out as well afterwards.

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But I do have a couple of questions for you and in the Meantime I see there's a couple of questions in the chat.

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But well put people you can either put questions in the chat or raise your hand using the under the reactions button.

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There's a raise hand feature, please feel free to do that.

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But I do have a couple of questions here. to start off for Alice, Julian and Hannah first, and one is that I know we've been talking about sort of clear requisition, forms, and telling you've talked about how the information is also

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used in lots of other contexts in the Ehr.

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In general. What would you given that you know a lot of There's a lot of discussion about how race ethnicity and ancestry are being used by researchers?

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And researchers are often not completely aware of sort of the providence of their samples.

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Where the labels get attached, how they get attached, What do they mean?

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What do you think is important for people who are using race ethnicity and ancestry data that come from clinical samples to know about sort of the processes that you've talked about about how these labels get

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attached, and why they get attached. What should researchers know?

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What would you want them to know? What should they be aware of?

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And how should they take that into consideration as they're using the data and doing analysis with it

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Anyone, any, any any of you or , I guess just going to that table that I had just being aware of how discrepant it can be at different points of care.

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I don't know if jillian you said this in your talk. My one of the most striking things you said to me is for billing purposes.

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People will just get randomly with whatever race qualifies for coverage. and you know it's never documented if they're actually that race or not.

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And, as I was saying, you might about that someone's race on the lab requisite form be different than what's in the Emr from their first encounter in the hospital, which may be been mislabeled and

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It's notoriously difficult to erase things in the Emr.

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It might be different from the pedigree that you send in as A. You know. Pdf.

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Printout that has those countries of origins that are more specific but maybe it weren't an option in the lab requisite form, I think.

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Just being mindful that how we document and collect the data and how it stays alive is very different, and what's searchable and findable is different than what's in media forms which is a lot of the genetics is such as

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it's really messy and I think if you're doing research alone, and not on an interdisciplinary team where there's people that are mindful of those nuances to help you clean up that data it can

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be really challenging to trust what you're finding I think the angle that I think about it from is even more like where it's going like being mindful of the consequences of the decisions that are made early on in research even

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basic research, but moving into clinical research. and the ramifications that they that may have in the future for certain population groups as to who gets access, and who doesn't.

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And so it's really striking to me I call out the example of policies related to coverage for Ashkenazi.

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Jewish individuals like. I think that the the way that research has been done in genetics over the last 20 to 30 years, in the way that in particular Ashkenazi Jewish populations have been represented in research has now set up for

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policies where there are tests that are covered. So even multi-gen cancer panels.

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Today being Ashkenazi, Jewish is sufficient to get coverage under Nccm guidelines for a test.

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Regardless of family history, because of the founder mutations but it's now been extrapolated for pragmatic reasons to coverage of all panels.

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But now we're calling out one group of people who get access when there are other populations that have founder mutations out there that probably just haven't had access to research in the way that other populations have and now we

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have policies that give access to testing based on that similarly We have a Cbt code for carrier mutations for reproductive testing for folks who are Ashkenazi Jewish.

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So that's a billing code that can only be used for people who would identify and present in that way. and as as Hannah called out like, That's That's their anec there their identification that may be based.

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In biology, it may not be it's messier than I think it was perhaps originally intended, but then has implications in the future around who gets access. and so I think it's really important for those who are sort of

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the stewards of that data who are or are building the pass for the collection of that data that is intended to ultimately drive policy to be thoughtful about.

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Certainly the folks who are included in the folks who are, but also, then how they describe it, how they draw their conclusions from their data, how they call the light the limitations of their data such that that can be considered as more political systemic sort

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of institutionalized policies Get rolled out that that's really that's really interesting.

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Sober, and thought Alice, my my response is one sentence race is not a proxy for ancestry, and vice versa.

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So that's the one thing for researchers to know that if there's information a medical record that is probably based on somebody's self identified race or a provider looking at someone and checking a box that that information should not be used as

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indicative of ancestry in research that that's a different type of information.

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Yeah, And I see comment in the chat, and a question for Larry Brody about inertia.

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And you know I was thinking about inertia. I came.

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I was thank you about a paper that written a long time ago, like 15 years ago, with Pamela saying, car we're we looked at

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How genetic researchers used race ethnicity and ancestry in their publications, and before and after some journals had had implemented some policies around the use of those variables and asking for you know,

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research is to justify and explain and give the rationale for why they're using racist and zoom ancestry.

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And also why they justify the use of the populations.

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And basically what you could see was inertia right so even with policies.

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They they didn't really lead to any change measurable change in the practices.

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And so this is something that I think we're gonna have to struggle with again, and and and probably worse in in terms of how data are collected.

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Especially in in health systems. but one of the things that Larry is asking about here is whether we can learn anything from the past about how the health system adapted to changes in the Omb categories which you know we were

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introduced in the late seventies. So one thing I just wanted to throw out here is I also noticed when I was going through some other data on on the use of race in other countries that in OeCD countries that they out

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of the 38 that were listed, which are mostly European countries, but not exclusively, but tend to be sort of wealthier countries.

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Only 2 countries collect at a sort of governmental, systematic level, both race and ethnicity.

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Data and Can you guess who those countries are so it's the us and the Uk.

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And none of the other countries do that. So I guess with that.

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Does anybody have any I wanna chime in in terms of answering Larry's question about whether you can learn anything from?

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You know what happened after the L. and D. categories, Do you wanna , want to chime in there we wasn't when they introduced Omb.

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Which is, I was around, but not aware but I didn't they change the Omb categories.

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Some somewhat recently in the last 1520 years to deal with Hispanic non Hispanic.

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So what what happened in healthcare system? I may be right about it.

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I may be wrong about that. But when they did what did health care systems do I mean the issues we're trying struggling with today have been around for a very long time.

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We need to try to force change and if the healthcare system overnight started changing their form. We can say they have that capacity, but I don't know what happened I mean.

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Maybe it took 10 years to have the forms be updated.

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They they do And it is easier with most institutions needing to be on electronic health record systems.

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Most systems have, you know, policy implementation infrastructure in place.

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We definitely have to deal with that with things like the curious act and other things that have come out recently of needing to adapt.

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How we do practice come up with institutional policies that are compliant with Federal regulations and and things like that, and train staff and implement it.

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And It's not right away, but typically there's some window of time where you're have a grace period to get these things in place.

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On hospital leadership will work to meet those policies.

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Training schedules for them, and make sure that they're compliant with us.

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That date the one it'll be fully implemented so there's definitely capacity in healthcare systems that change practice.

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And we'll talk about that a lot more in the third session, where we're identifying the considerations for making changes at the systems level hospitals, etc. But I mean I would say even if there is the

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capability in health systems, where there are medical electronic medical records that doesn't necessarily translate to the categories that are on the forms. And I say this because when we looked at the forms we found that they don't track

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always with what the census categories are some do, and others are totally different.

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So I think it's more you know that there are different.

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I love that. Hannah showed us all the different points at which this information is collected in different ways, and there is an even standardization right now across the board.

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So I doubt that changes to the census categories which do happen, you know, every 10 years when they when they do this review, there's a fantastic actually team of people who are who are involved with the census and

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updating those categories, and how how the questions are asked as well as well. but I I doubt that the census changing would change individual clinical labs.

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Forms for their test requisitions, even if the medical records changed, what they were doing.

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I think policy is interesting for genetics because it's different purposes.

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Technically right like in the healthcare system it's to be compliant with how i'll care is regulated, and it's for the purposes of getting demographic information and evaluating your programs and it is

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very much more focused on like help, disparity as evaluation.

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Clinical ads are regulated differently and the way that I I believe all the jelly needs to correct me.

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I'm wrong. a lot of the way. that this is pitched as mark for test interpretation.

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So on the forms it's not saying it's collecting like race information.

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Necessarily it's ancestry and it's for the purposes of having that.

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So as you're using like acmg criteria for example, and your patient belongs to a patient where media variant is enriched or things like that.

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It's more. I think the original intent was more for that, and because of a demographic program evaluation type of thing.

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How they have different get get away with having different regulatory standards.

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Yeah, I think jumping off of that, I think Certainly. the why is important.

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Why are they asking, and what are the incentives to ask and understanding those?

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I think, before I was talking about them as much as consequences of of how things have come out of research.

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But I think they also can be thought of as incentives for certainly for payment systems for people who will get insurance coverage for insurance, reimbursement, and and perhaps and i'm terrible at idioms.

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But perhaps this is one of those like, How do you like hurt cats?

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You move the food kind of a thing like you change the incentive structure.

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You get rid of the cpt codes that are specific to certain groups of people?

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And you continue to pass on the reduced cost of sequencing to the clinical space.

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Because I think a lot of these guidelines and criteria come from a perspective that you know genetic testing needs to be carefully controlled, or we need to manage costs around that as the cost of testing goes down I think

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like those concerns on the part of payers and other systems start to decrease, and that's part of what moves us towards a space where expanded carrier screening is an option over ethnicity based

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carrier screening. we're starting to see some commercial payers already move in that direction in part for justice reasons, because they recognize the discriminatory aspects of an ethnicity-based screening.

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Approach, but I think it really helps them along. when the cost of testing goes down, and it's not a hugely different cost between an expanded carrier screen and a 10 or 12 gene ethnicity based panel and I think in

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hereditary cancer, too, I think i'm hoping imagine is sometime in the next year, or so we'll have guidelines that cover all patients with breast cancer.

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For instance, coming out, and then we start to move those away from race or in the city based criteria for coverage.

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And I think, as the test cost of testing goes down, it becomes also easier to implement those sorts of things

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Anyone else feel free To Oh, oh, please go ahead! Good net! Hi!

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Everyone. my name's lynette i'm in charredo. i'm information and science person by trade, but I worked in the I'm a postELSI.

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Postdoctoral research fellow at the University of Michigan And I just think that it's really interesting that we're talking about this because a lot of times people wonder like what is it information science is doing in the social science of

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genetics. but I think that we see that there are a lot of layers to this.

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One thing, though, I wanted to say is that we want to be mindful.

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I think about the the utility sometimes of looking at population data and trends, and some of these categories to make sure that we are still recognizing, like some of these legacies of inequities, and making sure that like I understand that

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there's a there's a a good heart for us to be like pushing forward and making sure that we're making it more scientific, but that we're also looking at some of the social implications and the ways that

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people have been marginalized and discriminated against, and in such that they have not had access to certain types of care.

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And so in recommending that you know maybe we become more open or change things, that we also are mindful that you know we can use information to just try to provide more guidance on how to use the information and that maybe

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there's some of those categories should be intact, but maybe not used as proxies for things that are more clinical or more scientific, but rather for other historical trends or things, like that and I

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just wanna make sure that we keep that consistent and mindful that there are some other uses for those kind of it will be categories.

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Thank you. . Oh, go ahead. I just gonna chime, and I I completely agree with that.

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And I think, think about it a lot in my role because i'm kind of in this middle ground of thinking about things from like a clinical perspective and wanting to provide person centered care. and for a lot of reasons you know the way that

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we talk about this isn't helpful for individual people and we just need to ask what we need to ask and ask about how they think about culture and family.

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We largely don't use their answer straight for interpretation.

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We use population based numbers of frequencies legal frequencies like we don't really need to have some of these conversations.

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But how do you balance that from more of a population health perspective, where race is a proxy for a lot of power structures that we have in place?

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Because we don't want to erase that history either So how do we like fit current need and modern conceptions of these things without erasing history?

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Because we haven't solved those problems yet and I think it's interesting to try to think about how we continue to collect that, but have more productive ways of collecting new types of information that are more productive But Yeah, hopefully throughout

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this series we'll we'll start to answer some of those challenges

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Question from Kim off. Yeah, I totally agree with everything that's being said, and thanks so much for initiating this conversation.

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As a genetic counselor, I have to say a lot of people don't understand what we're asking them when we ask for race ethnicity.

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Even ancestry or country abortion they just don't know they don't have that information.

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They don't understand the terminology which is what we're talking about, because there's so much complexity behind those terms.

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But can we just talk a little bit about the fact that a lot of people don't know how to answer these questions, and that's another complication of trying to get down to the root of what's going on So how do we as as

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healthcare providers. How do we frame this to?

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To patients. We need to agree upon language within our own community.

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But how should we be talking to patients about this, and and how should we encourage them to get information without promoting things like direct to consumer testing?

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I can speak to that. Certainly I teach a class and some of these topics within the genetic counseling program at Vanderbilt and I To me the key thing is understanding at the core.

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Why you're asking that question and very specifically toy if it is it towards a risk assessment question, then being very clear and transparent about that, and collecting the specific information that you think you need to ask that question and

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being clear that it is an evidence based risk assessment too, and making sure that you're gonna ask that question. If you're seeking to document the racial disparities in the population of patients that you're seeing like you

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would ask different questions, and for different reasons. then if you're seeking to do a risk assessment based on genetic ancestry.

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And so I think, being just crystal clear on your goal and your purpose, and even with your patients being crystal clear on why you're asking and giving it that level of transparency and genuineness is a part of

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building a relationship with the people that you're seeing and being clear and transparent about it, which makes it far less suspicious, and probably also helps them much better understand what it is you're trying to learn from them.

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I think, curious to know from the audience that there are clinical geneticists

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Out there in the audience, or others who interface with patients. You know.

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How have you thought about that question, or handled it

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Well, I wonder if please feel free to jump in if you absolutely think of something.

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But I do have a question for Lenette.

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Because as a data scientist, I'm just sort of listening to what Hannah and Philly are been saying and what you said. and i'm just wondering as a data scientist, how do you sort of think about a

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react to this idea from a data integrity. point of view about I mean and in fact, so i'm So i'm hearing a lot about how, and we've there's been a lot in the literature about how these categories

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you know people don't actually know what they are and I don't.

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I would argue it's not just patient who don't know what these are.

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I think nobody knows what these are. And so you know that introduces a huge question in terms of you know the integrity of this data. What what is it?

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And so. and this is obviously this: is not an issue that's just about race ethnicity and ancestry.

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This is about all kinds of data and there I know there's a lot of discussions about ehr uses national language processing.

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There's a lot of ways in which data are very messy, and I know that those recognition of that and ways to try to deal with that.

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Is there a conversation in the Data Science Community about how to do this for race at this and ancestry?

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I think we kind of have to reconceptualize data a lot of times in general, just how we're thinking about things.

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We always have these kind of 2 d models right we have an x and a y, and we're always trying to just propose something in contrast to another thing, to understand it.

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I think that's just how we're taught to think about things. you know we always have something that's black, and something That's why something that's good something that's bad and Then we're comparing and seeing

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how the differences are in between I don't think there's anything wrong with that.

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I think the challenge comes in is that when we have this layer of stuff that we need to unpack, which are usually like our social things, that we've been conditioned, and we all have it I think that I think that this illusion of

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neutrality that we have sometimes where we think that Oh, well, no!

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Even even in this idea, that we're talking about Oh, i'm using this data for clinical meetings or I'm using this data for social means, or I'm using it for scientific research.

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I think the challenges is that there's no nothing is these things are all intersecting, and so I think someone had said earlier, talked about the interdisciplinary nature of things, and making sure that we have more

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representative people. And when I say that I mean on all levels like, so that we can hear the size of like Oh, when I look at this data, this is what it means to me from this aspect sometimes we think we have blind spots in

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terms to how our a data will be used and one of the things that I would love to see is just. and I think from we're talking about costs and things like that is just building efficiencies in our data and understanding how we can

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share and use data more efficiently and and that but that doesn't mean that it's not going to be more complex.

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So that's what I think people have tried to do is oversimplify humans and populations to me a complex thing that was their approach to efficiency.

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And it's not necessary we're seeing that now that has its own stumbling blocks, right? And so if we were able to do things just like you're doing right now where we have like these folks from different backgrounds and thinking about

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these gaps. That we have in the ways that we're not able to ask certain questions, because they do have implications, and I think that's something that we're seeing a lot of times.

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People like. Oh, I just do vent science I don't really have to think about

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I don't really have to think about the social implications of this, but actually, I think it's something that we have to be mindful of and or involving people that live the experiences and taking those things into consideration ie you

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know patients. There are plenty of patients who are so citizen data sciences.

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There are plenty of people who are working in new spaces that maybe aren't as knowledgeable about ethics or ethical dilemmas, and things like that and I think that there are opportunities for us

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to approach these things from an interdisciplinary way.

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But I unfortunately, I think the challenge the biggest challenge is that I don't think that it's going to be necessarily easy.

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So if we approach it like with this idea that this may be a big, hairy, audacious goal of kind of figuring out ways to work in a new models that are not

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So like with these bigger interdisciplinary teams and work through that process of what does that mean?

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And the pushing pool with that then, I think we'll probably see some more.

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I guess improvements and some of the things but it's something across the board, you know.

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We know that Well, we create algorithms and we're doing different things.

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It's all based on how the data was collected it's all based on how, who's represented in the data?

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And then it's also based about what assumptions and rules and theories that we have underpinning.

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Why we're making some of the predictive models that we're doing so.

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I think I think all of those things are all falling into the same thing, and everyone's having these discussions.

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But it's it's nice to see that we're bringing more people to the table from different backgrounds to talk about the impacts, because sometimes you know someone like myself in the past.

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I may not have had a as a and awareness of what's happening clinically, whether it's from the patient side or from the side of the clinicians and providers that are interacting with these systems and then thinking

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about how inoperable they may be, and how patients and just everyday people want to get more information out of them.

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I feel like there are opportunities that we can do a better job, seeing the value of our data, because I think we everyone realizes that it is very valuable.

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And some of these things that we've been talking about like knowing your family health history for or you know, just being able to. You know, map ancestries and create these really complex same family trees are really advancing how we are even able to

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study variation and diseases. that we're trying to cure.

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So I I think there's a lot of opportunity I think we have a lot of wait.

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Wait to go, but probably you know that same where it's like we may be able to make things less complex.

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But we may not be able to make it simple and so that I feel like That's a lot of what is happening here.

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And so thank you for having this conversation

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Marin Tuner, are you? Are you still there?

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I saw that you had some questions in the chat and partly in response to Alice's question.

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Did you want to say more about that? Yeah, Well, I don't necessarily mean to say more.

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I think this was a great discussion and i'm really excited to hear everything, and it's just I think I heard that you know.

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Just what do we say to patients when we ask these questions like, Why why are we asking these questions?

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And I generally say that it might be helpful when the results come back to to you know, in my interpretation of what a variant might mean, or might not mean so.

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But I but I think i've heard others in the conversation say that you know it doesn't for any given individual patient.

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It. it isn't perhaps so important to to have that information but but sometimes it can be useful.

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So that that was all I needed or wanted to say.

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Thanks. Good to see you here. before me close. I also just wanted to mention to that question of how we ask, and the lack of why.

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Often I mentioned in my recording There's a lot of ways that our systems are talking about Ra.

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Falls apart for people. So i'm by racial thinking about multiracial and how multiracial people go through the system is an area of interest for myself.

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But I think it also falls apart when you think about like adoptes, and they might look a certain way and be ascribed to race.

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But they don't actually know their ancestral origins You don't. If they're adopted into a family of another race, are they subject to the same kind of systemic barriers of people that belong to that

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race. Our immig, you know, immigrants and being first generation.

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That's a whole other kind of worm so I just I think we often lose sight of the Y. and we can't assume that race is correlated with culture is correlated with people's concepts of family people at

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blended families. Now there's just there's a lot of complicated things, and I think historically, a lot of these things did merge together.

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We could kind of and waiting around, but they're talking about and these race is a very imperfect proxy for a lot of things.

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But I I do think it's. changed a lot and we do need to start focusing more on the why and just asking what we mean for it to be more inclusive.

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Because there's a lot of people that don't fit into this system anymore.

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Absolutely. You could have a whole other conversation on that and maybe we should actually

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So as I. I think we have to wrap up here.

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I really wanna thank all of you, and also urge everyone to join us again.

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On may sixth for part 2 of this conversation so this isn't over yet.

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And it's at the same time same place and also please.

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We'd appreciate your feedback on these through the survey that's in the chat, and do news also put in the link for the registration for next time.

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And as always, you can email us the info atELSI.

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Hub dot org, And finally, I just wanna reiterate that if you have any ideas are suggestions for futureELSI: conversations.

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Please let us know. thank you again to Alice, Jillian and Hannah.

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This is a fantastic conversation, thank you so much. Mildred and Sandra lies on here as well.