WEBVTT

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Hello, I'm Mildred choe and I'm Delighted to welcome you to our third and final Lc.

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Conversation session organized by Dr. Ellis Popejoy Co-chair of the Clinton Ancestry and Diversity working Group.

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And this Today's session is entitled revisions to demographic representations on clinical lab requisition forms.

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Lc. Conversations is a series of networking events to promote engagement on Lc.

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Issues, and we welcome your proposals on new conversations they're hosted by the Center for Lc.

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Resources and analysis, or Sarah, which provides resources to support research on the ethical, legal, and social implications of genetics and genomics, and connect scholars, scientists, policymakers, journalists, members of the public and others, to

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engage Lc. Issues series funded by the National Human Genome Research Institute at Nih.

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And is managed by teams at Stanford and Columbia Universities in partnership with the Hastings Center and Harvard University.

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I encourage you to visit Sarah's online platform Lc.

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Hub dot org for the recordings of these series and I really hope that you got a chance to view the background videos by our panelists today.

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They're really fantastic, and those are found also on Lc. hub dot org.

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Please also go to the website to join the Lc. Scholar Directory.

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Sign up for newsletters or other events like this at Lcap dot org get daily updates and news on Twitter.

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So for today's session it's an hour long and it's intended to provide a for for audience questions, comments, and discussion so to participate.

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Please use the hand. raise feature at the bottom of your zoom.

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Screen or enter questions and comments into the chat, and our moderator will call on you.

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Please remember to lower your hand after being called on. we encourage you to turn on your video to facilitate discussion. and please note that we we will be recording this session, and the recording will be on Lc Hub dot Org

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If anyone needs support, send a direct message in the chat to Dounia Alami Nasif, or email info at Lc.

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Hub dot org, so It's not my pleasure to turn the floor over to Dr.

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Alice Pope Joy, who organized the series to introduce the session and our Moderator.

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Thank you so much, Mildred, and thank you so much to Elsie Hub for having us here.

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I can share my slides, can remember and see

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Okay, So Today we are fortunate to have speakers talking about changes to clinical lab reposition forms.

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But this has been part of a series. that's been ongoing the spring race ethnicity and ancestry on the clinical lab test Requisition forms and a lot of work has gone into creating this

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Lc. Hub Series, not least of which are members of the Clin, Gen.

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Ancestry and diversity working group, who all highlight in a moment.

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But just to say that Clinton is a large resource with lots of different activities and working groups with our steering committee members listed there, and there's a great support in Clinton for the work that we've been

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doing since 2,017. So our charge, when we started as the ancestor University working group of Clinton, was to provide guidance on the use of diversity data like race ethnicity and

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ancestry for the clinical Genetics community.

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So you can see here there are a lot of different professionals and expertise here on our working group, from disciplines as different as historians and bioethicists to a jack epidemiologist

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statistical and population geneticists, social scientists, genet, counselors, clinical genesis.

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So we have a huge array of backgrounds and expertise represented on our working group.

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So we have been really motivated by a series of questions in this Lc.

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Hub series is also Conversation series. and the first is that we need to know how the information on clinical lab test requisition forms is used.

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Actually in actually using clinical jacks practice we also need to know what the most important information it we really are looking for in clinical genetics.

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What's necessary. When is this information absolutely critical versus what is it actually potentially harmful?

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And when might it be harmful to not have this information?

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And finally, if changes to these forms are to be recommended, what do we need to consider?

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As we are working towards implementing changes, what are barriers and opportunities.

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So. So we designed this Lc. Hub series to sort of address.

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Each session would address those questions. So the first one we did was on context for the forms.

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The second one was on really digging into the type of information that is on there, and what's potentially useful or not useful.

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And today we're going to be talking about revisions to demographic representation on clinical lab requisition forms.

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So I hope you did get a chance to watch the the talks in advance.

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They're fantastic, very informative and if not That's okay.

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They're recorded and you can watch them at any time i'll see how website, So I have a a few questions for you.

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Sort of an interactive format to get us in the spirit of interacting, since we will be having a discussion later today.

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So I want to throw this out there, and we ask these questions.

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The very first session. So if you could the instructions are here at the top to access.

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Pull everywhere. You can do this online com, slash, Pope Joy, or you can do it, be a text message.

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You can text Pope Joy to the phone number listed there.

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747, 4, 4, 4, 3, 5, 4, 8,

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So please let me know if you cannot see the instructions. but otherwise, if you can join the session, you only have to do this once, and then you can answer each of the questions afterwards. The first question we'd like you to answer is

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which words or word come to mind. When you think of a population

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Okay, something you can't see the instructions sorry about that.

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So this is

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Okay, seeing some people bugging in now

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I see lots of group underrepresented ethnicity people, location, characteristics, location, cohort, migration characteristics.

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Individuals, arbitrary national sense, unity. so lots of different ideas about population.

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Thank you for sharing. How about race? What does the word race mean to you?

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Someone was saying in the chat that they couldn't see the results?

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Can you see them now, or just still know you cannot see that.

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You know

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No, all we're seeing is the question okay

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Why don't we do this

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How about now? There, that works fantastic

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Societal groups, Skin color, sociopolitical, historical, construct, Omb.

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Categories, social groups. Alright, thank you for sharing.

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How about ethnicity?

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Okay Heritage group to find my language and culture Ancestral origin. Hispanic, not race. local genetic background group is in our culture, ancestral background.

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Historic background belonging community. Alright, thank you so much for sharing.

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And finally, oh, ancestry! what does the word answering into

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Seeing lots of family lineage, genetic heritage, genetic origin, history, family trying to get background, statistical analysis, geography.

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Alright, thank you, and last, but not least we'd love for you to share with us how important you think it is to have population descriptors like racism and ancestry on clinical lab test acquisition forms

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Okay,

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Okay, thank you so much for sharing At some point I would imagine we will do something as a result of this.

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Maybe a publication of some sort. So I look forward to sharing that with you all in the future.

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So I would like to now introduce our Moderator for Today's session, also Vcuing, who has been a a fantastic contributor to the Industry University working group of Clinton almost since it's

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beginning and she has a long history of expertise in the health equity space. So she's a health equity, geneticist and certified genetic counselor at an end, tech and definitely has a lot of depth of

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expertise in the ethical, legal, social implications of genetics and genomics.

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And has experience in equilibrium equitable implementation of personalized medicine and doing research, ethics involving inclusion of diverse populations of genetics, genomics, and in biobanking so we're

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very fortunate to have all to be with us today in moderating the session, and love for you to take it away.

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Thanks so much, Alice I surely appreciate it and thank you to Sarah as well as the ancestry and diversity working group.

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I'm really happy to be here and just really elate it to see such an important and necessary topic.

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Really race and elevated on the platform, so that we can increase awareness and ultimately continue to take more actions.

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Moving forward. So today it is my pleasure to moderate our conversation today around the revisions to demographic representation in our political lab requisition forms, and we have 2 phenomenal presenters who uploaded and recorded

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presentations, and again, if you get that, she has to check them out, please do so.

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I learned a ton in each of the presentations, and and there is definitely some relevant information that we can implement and incorporate in our clinical practice today.

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But today I have the pleasure of introducing our 2.

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Speakers, and then turning the floor over to them to provide an overview of their presentations.

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Our first speaker is Laura. Do you quit Lastio?

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She is at the University of Utah, and she's also an employee of A.

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R Up. laboratories Today she will present on the challenges and implementing changes in the collection of race, ethnicity and ancestry, data and test requisition for, and then our second presenter today will be

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announced, Who is that in Bt. in her presentation will be on standardizing lab requisition forms for hypertrophic cardio myopathy, a clinging in cardiovascular disease working group

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initiative. So, Laura, I will turn the floor over to you.

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Thank you for that wonderful introduction. Let me share my screen.

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Are you guys able to see that wonderful Thank you? so much for inviting me again to participate in this series?

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I'm so excited to have some extra good discussions today. So in my recorded talk, I discussed some of the challenges in implement implementing changes in the collection of race ethnicity and ancestry or ra data in

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requisition forms in the setting of a large reference lab.

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So first, I kind of started with the visual representation of what in the Us.

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We consider our race and ethnicity categories, and how they have changed over time in the Us.

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Census. So, as you can see, there's constant change and even the census acknowledges that this is these categories are based on a social definition that is established in this country, and and I

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also wanted to kind of pick you back off of something. Dr.

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Mcnight said previously that although we sometimes think about data as patient reported, it is really reported by whoever is filling out the requisition form.

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I also wanted to briefly discuss our review some of the perhaps perceived barriers that we can face from a regulatory standpoint.

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So this means things like Cap clea and you know, as part of cap accreditation.

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We not only have regulations that dictate how we control our documents, how we make modifications, how long we retain them, but we also have some requiredments or recommendations regarding what the content of the documents has to

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be. So I searched. We searched for race ethnicity, racial ancestry, and we did find that there were some requirements or recommendations surrounding, including this information and requisition forms not just in the molecular

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checklist. This is one of the points in the molecular checklist.

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Also within the molecular checklist, when it comes to variant interpretation.

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Again. these terms start popping up again. allele frequency and specific populations.

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Race ethnicity. and it also makes references to published guidelines from other societies.

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And then, because we're in a reference, lab in my case, we not only deal with genetic testing, so a lot of times, if we want to make changes at a large scale, we have to consider the requirements of other the requirements from other

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parts of our laboratory, and in this case. something that's kind of closely related to genetics.

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But maternal serum screening has very specific recommendations, requiring patient race being in the requisition form, as well as the having procedures that determining why we are or not, including patient race in our adjustments of multiple

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Medians of the mean in afp, etc. And obviously this ties into the fact that some of our guidelines for variance, interpretation, use the words race, ethnicity, and ancestry seemingly

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interchangeably in the case of the maternal serum, screening even the 2,020 guidelines from Acog, and the Society for Maternal Fetal Medicine, include things like letting us know that some of

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the factors. Aside from the map markers were actually measuring.

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Some of the eternal factors are considered, including race.

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So something that I found super interesting was the process of actually I don't know why my slides keep changing on their own.

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I'm so sorry the process it's likely that you have timings which is the default.

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If you have a lot of slides you can just exit out and unchecked.

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Use timings in the slideshow and it'll stop doing that?

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Oh, gosh, Yeah, let me let me see. , unfortunately, Powerpoints default.

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No one ever knows Why, but that's that's not good i'm So sorry, guys.

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So you go under slideshow. Give me 2 s.

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Oh, rehears timings now, i'm not sure i'll just share my slides with you guys over here.

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So I think this. Can you see that this was probably the most eye-opening part of this whole process was seeing what actually needs to be done in order to complete the change process for my reposition? form?

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And I think there are 3 very specific times at which this takes the most collaboration.

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And then you know that we need the most effort. So, recognizing that there needs to be a change, and I think, in the case for race ethnicity and ancestry, a lot of it is changing the attitude of providers

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clinicians, researchers towards the importance of this information in test interpretation, then the modification of the form requires multiple people.

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There's typically task force or committees that come up with these classes, or what we are actually going to do modification-wise.

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And in our case it also includes a review. After we have put our part, and because we have some corporate white templates, and people are perhaps not expecting that we are going to make changes not only to the content of the patient history form but to

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the demographic section some of our changes if we're not super careful, are just going to be reverted back to whatever the corporate template is, and that I found fascinating.

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And it didn't just happen to me while I was doing some changes in biochemical genetics.

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But it actually happened to some of the other requisition forms that we had been updating, and that was extremely interesting for us to see.

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So I think those were some of the main points that I wanted to make. as I think everybody here is, is fully aware.

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We think of race and ethnicity, and these are social constructs.

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Specifically the Us. Centric Omb race and ethnicity categories, our social, cultural and don't have any biological basis.

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Finally, I think something that we we all agree upon is that our laboratory practices are not just informed by social changes in the environment, and like people being loud.

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But we actually need to follow quality and compliance requirements, and we need some guideline guidelines and and some guidance from professional organizations.

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Because otherwise I don't think we we are necessarily going to be able to overcome some of these barriers.

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And I wanted to thank everybody at air up. That helped me with this project.

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And happy to answer any questions after that. Sorry for the technological Hicks.

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Thank you so much, Laura. That was phenomenal. Alright, Anna, I will turn the floor over to you for your your overview, please.

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Thank you. Can you hear me? Well, yes, we can hear you great, and you can see my slides.

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Yeah, we're good. , Okay, so I will give you a quick summary of my presentation.

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But before again. Thank you, Alice, and the organizers for the opportunity to present this work.

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That I started before joining in bte and finish while adding vta

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And it was focused on standardizing lab wreck forms for hypertrophic cardiomopathy I'm.

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Also a member of the Clinton cardiovascular disease working group.

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And there purpose of this presentation is not so much to take you through the

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You know details of hypertrophic cardiomopathy and the cardiovascular data.

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That was the center of this work. but to show a framework that we use to pull consensus from different leaders in the field.

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On standardizing requisational forms. So it all started in 2015, when the guidelines for band interpretation by Acmg and Amp came out, and as part of our group, we were actually working on updating the Varian

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interpretation guidelines for hypertrophic cardio myopathy. And as soon as we started doing our work we knew that we had a problem which was that we needed data and order to call Case segregation the

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noble evidence for the new guidelines, and we also realize that different labs had their own phenotypic data.

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But there was no consensus as to which data labs were collecting for vent interpretation.

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So we were trying to pull case count, and the noble counts and segregation counts, but everybody had their own way of counting cases.

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So we came up with a solution which was to come up with a phenotypic data set for Hcm.

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Bear interpretation that would be sufficient and essential for brain interpretation.

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So the idea was that perhaps labs were collecting too much information that was not needed, and in doing so, perhaps also missing essential information that was essential.

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So the work led to a publication in 2,021, and, as you can see, it involved different labs from the Us.

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And around the world, both academic and industry representation. Thank you.

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So. I would like to spend some time here in the consensus building process, which I think maybe what's probably most important for this group.

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The way that we approach. This was first of all to our knowledge.

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It had never been done before, so it took multiple iterations and conversations.

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And you know brainstorming, how can we do something that makes sense, and can resolve in a consensus at the end?

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So if you follow the pyramid from the bottom. First, we gathered a group of experts from the group and just ask them, you know, from your knowledge of clinical notes as you see patients and test recreation forms and interpreting genetic

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testing results. What do you think may be the most important for their own interpretation in terms of phenotypic data.

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And that group came up with 18 data elements. at the same time, but also represented here.

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A step number 2. We wanted to confirm that we actually had a problem.

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We thought that lab requisition farms were all over the place, but we went in and sought data by downloading test requisition forms from laboratories that were offering pretty much empathy genetic testing and then in step

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number 3. we run a pilot study, and this was in collaboration with the lab for molecular medicine.

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At Harvard we pulled 50 Hcm. cases, and using the expert derived list, we just counted how many of those 50 cases had that data represented, and also on the reposition forms?

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How many of those elements were also represented just to evaluate.

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You know, General provider compliance, and how realistic it would be to collect some of the data elements that the expert group recommended.

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And step number 4. We went to lab directors who were participants of this particular working group, and we asked them for team questions, addressing the utility and visibility of you know, of obtaining the data that had been recommended by

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the expert panel in Step number One. So from that step the list from the experts was narrowed down from 18 to 11 data elements just based on feasibility and opinion of what may or may not be essential for vain

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interpretation. And then the core working group we got together, and, you know, pulled all these different lines of evidence to come up with a proposal for the larger working group on what may be the phenotypic minimal data set for

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Hcm. bar, and interpretation, and that was another survey to the entire working group in this project, where we provided a proposal of what those elements may be, and also some recommendations for the group and for the field in general

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seeking endorsement for the idea and and the concept behind it.

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So in this slide, just quickly showing the white divergence that we observed in different laboratories.

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9 of them were represented, and here is also part of that table, but showing at the top how it looks like for demographics, including ethnicity and ancestry.

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There was more consistency in laboratories collecting this information, whereas for cardiovascular data, we saw less consistency.

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Jumping to the final consensus to be brief in here we can see.

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Let's go to bullet number like second to last what was the final consensus.

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We got full endorsement for recommendations, including that there should be a consensus on which data elements should be standard fields on reposition forms.

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The expert panel considers the minimal phenotypic data elements as critical and that this data should be provided by clinicians when ordering genetic testing.

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After that survey that we launch where the proposal for the minimal data set was presented. We had a call to confirm that everyone was on the same page and seek additional input and before we lock down the process and during

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that phone call. the vote was made to further reduce the list from 11 to 9 elements.

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So we went from 11 from 18 to 11 to 9. As part of this process.

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The final module that we came up with with the 9 elements is shown here at the top.

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The essential elements at the bottom, the non-essential elements.

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And, as you can see, the group, all in consensus, recommended that race and ethnicity should be collected for greater interpretation.

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As you can also see in the slides. What we used to come up with the categories was the Nih.

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Reporting categories for race and ethnicity.

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There was no discussion or pushback on the idea. It was at the time what most people felt was the standard, the right thing to do.

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But of course I look forward to discussing this further as part of our event today.

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And you know, get more into what led to to this decision, and what it means today.

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In retrospect. there was also as part of the process.

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We asked the labs who would eventually be implementing this.

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You know how. How would this look like in real life and while there was consensus?

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There's also the issue of implementation. so some of them qualified their responses, saying that they would need you know, review by clinical expert information, technology or corporate approval in order to actually implement what they thought was the right data set

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for interpretation. So in retrospect, I would say that diverse stakeholder involvement is key.

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We had a diverse stakeholder group and

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We were fortunate to have that type of representation.

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It was time consuming and something's challenging as an iterative process, multiple conversations, multiple perspective, generate counselors, cardiologists, lab individuals, people from different parts of the world.

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It was very interesting to be able to navigate all those challenges.

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The race and Ancestry collection you know in retrospect. This is something that was done between 2,016 and 2,019, and the Nih standard was recommended without contention, which I think it's a

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topic for discussion now. and then. implementation so you know we published, but I don't think that was sufficient to this date.

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Implementation of that module has not taken place. to my knowledge, none of the labs that participated, or others have put this module on their recommendation forms.

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I would, you know, like to have some studies on barriers and drivers maybe concurrent, if I had the opportunity to go back.

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And then also work actively on uptake enhancement efforts.

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And I think these are lessons that could be applied to future efforts.

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So i'll stop here and look forward to the discussion i'll stop sharing.

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Thank you so much, Anna and Sharon. I see your question in the chat, and I will definitely incorporate that during our our moderated discussion.

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So I have one slide that I want to share with the audience today.

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So let me share my screen

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And can you confirm if you're able to see my Powerpoint slide.

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Okay, and then let me minimize this. So this is one of my favorite quotes by one of my favorite people in the whole white world, and the quote is the future never just.

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Happened, it was created. And this is a quote from Dr. May Jemison, The first black female astronaut, is position engineer to travel to space and specifically on mission space shuttle endeavor.

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And for me this quote resonates because I think we are in a moment in society.

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A moment in general genetics and clinical genetics, where we are intentionally creating the future, but really creating the present that we want, that we need.

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But most importantly, that we know that patients and populations need.

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And this is a future in which, hopefully everyone will be able to benefit from the advancements into that extension.

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They'll mix. So I just wanted to open today's discussion with this quote, and I also want to commend stop screen sharing right, and I also want to commend Laura and Anna for your presentations for your thought leadership

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today, and for your bravery to really take a stance within the field of genetics, to implement something that we know is not easy.

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But at the same time it's something that We know is needed, and and that really needs the momentum behind it, so that we can generate again the data that will that is needed to benefit more patients.

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So I will open the floor. please. audience members, as you have questions, please feel free to incorporate them into the chat, and I will leave them in to our moderated discussion today.

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But I really wanted to open the floor with a question that is really centered about the fact that we are no longer in a moment, but instead we are truly in a movement within society and within our world, in general and I wanted to start by asking

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Anna and Laura, if you can both speak to what are experiences in your past, that seed it, your courage, and your desire to take on projects such as the ones that you presented to us today, and then also an explaining

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some of that courage that seated that motivation.

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If you can share. if you ever encountered any resistance and really implementing an executing those efforts as well, I can start

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So to me. it's a personal issue I joined the genetic counseling field.

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Almost more than 20 years ago, and I always felt like an end of one.

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Everywhere I went, and the more I started studying the literature and got involved in research, the more I started paying attention to the discrepancies, and, to be honest and blonde the nonsensical way in which data was

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collected regarding race and ethnicity and feeling.

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Like none of the categories often would apply to someone like me. and so I felt like by being this, you know, unique sort of n of one individual and character in the field also allowed me the opportunity to get used to thanks some leadership role even

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if I had no leadership title. I was just, you know, representing one line of thought, one experience, and, you know, learning to speak up from that perspective when the opportunity to start working on their own interpretation for the clinging nih

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initiative. and eventually this work on implementing a phenotypic data set for Hcm.

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Barri interpretation. It was a hard, challenging project, but maybe something that was already kind of charted as part of my path.

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And just you know I had been training for it. I would say up until that moment.

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Awesome, thank you, and Laura would you mind answering that question as well. Yes, that's that's a huge question.

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So it's it's kind of a an entire personal journey so I'm.

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A foreign medical graduate, I'm born and raised to the medical school in Guayaquila.

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I spent the first years of my pediatric medical training in the Midwest, just trying to assimilate, trying to just blend in.

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Not get in any trouble, not say anything about anything and not being the token for a medical graduate. right?

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I was just like i'm gonna do my work go in go out

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And then you know every time I fill a form i'm like faced with language that I've never had to use.

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I've never had to describe myself as hispanic where I come from.

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We speak Spanish i've never had to describe myself as latino i'm ecuadorian that's what I've always been.

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It's always been super like complicated i've probably ruined everybody's data by answering something different depending on what box was there or was not and trying to remember like what I answered last time and then when I saw some of

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those things happening in like forms and research or trying to like how harmonized data, and not knowing where to put things, or speaking with my friends who were like, I have a friend from Egypt, and he's like Yeah, for forms apparently I'm white I get none

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of those privileges. but like that's what i'm supposed to identify as like all of these little things along the way.

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But I was actually talking to Dr. Poke joy about this There's there's a lot of barriers of trying to be loud and open when you are dependent on the Federal Government for your training and your immigration

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status. So I wouldn't say i'm as vocal or as much of an activist as I would probably like to be

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But I think those types of issues or things people don't necessarily consider when when they're trying to have a a journey into diversity, equity, and inclusion, research or advocacy is that you know sometimes we do want to just

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blend in and not get in trouble. as sad as that might seem.

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Thank you both. Your your responses were they both resonated with me, especially as a woman of color.

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I am also very passionate about this space, because similar to your response, Anna, I did not see myself represented in the work that I was doing, and I was motivated to go into the space to help serve the populations.

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That I knew were underrepresented. and I just instantly noticed that there was much work to be done.

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And Laura as you spoke, and especially thinking about your your training as a scientist, and thinking about your responses on your clinical profiles, and in reflecting on what are the boxes that are available, and then trying to

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recall. What did you share in your previous profile that's a lot of stress, a lot of stress that a patient should never have to take on.

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But as you spoke, not only did I reflect on the populations that are underrepresented, but it also made me think about the populations that are misrepresented, based on those check boxes that we are making available.

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To date. So thank you. Thank you very much. Another question in Laura.

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I will direct this question to you is pretty long. So bear with me.

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Do you think that the recent calls to move away from race based medicine standards?

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That recently the American Academy of Pediatrics issued on May second and then we also had the University of Maryland medicine's.

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Recent announcement to officially eliminate race as a factor in burning decisions.

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We also have the New England Journal of Medicines, provision of new and more accurate egfr equations.

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That no longer require race. Do you think all of these efforts in across the spectrum?

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Will these actually push labs to actually make changes to their laboratory practices?

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That is an excellent question, and I think we kind of have to separate, too things.

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I think the Ap. call to action is one thing, and I think calls to action are wonderful.

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But that doesn't mean change is going to happen I think on the other hand, and Ary P. also as an example, and I think Uc.

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Davis already got rid of the race based adjustment for Gfr.

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When the National Kidney Foundation and the American Society of Nephrology made this task force to reevaluate their their practices, and they came out with an official recommendation that makes changes happen and even here.

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So obviously we are. We are a venture of the University of Utah, and our our medical directors here are faculty there.

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So when when Dr. Kamisha johnson davis one of our medical directors here was moving towards implementing these guidelines and removing the race, based calculation, it it it's a whole ordeal.

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So it's committees it's giving grand rounds so that the people ordering the test, understand why these changes are being made and like why they're test is going to look different it's talking to leadership like talking to

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clients, because, you know we we are a large national reference laboratory.

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So all of our clients have to change their interfaces.

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How the reports look, and I think that a lot of those things just just hoping them and willing them to happen, is not.

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It's just not enough. So I think call to actions are great, but I think guidelines are what makes a difference in in reference laboratories.

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Thank you. That really highlights the fact that so many stakeholders have a role to play in really initiating this change, this necessary change.

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And it really speaks to the process of management and the fact that it has to be a collective effort in general.

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So thank you so much. anna i'm actually going to ask you 2 questions right now.

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I'll start with sharon's question just because it's specific to your study.

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So in the chat share and ask if you can confirm whether individuals had the opportunity to check more than one category.

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For instance, canon ordering physicians select Hispanic and black African American on the in the study that you That's correct.

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That's not written on the paper explicitly but the way in which we had all been using those categories would have allowed to a matrix of multiple choices for for individuals.

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Thank you great. And then the other question that I have for you is, why did the panel feel the need to include race and ethnicity as a central for variance and interpretation?

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Yes, So first of all it's stated in the Acmg. guidelines lots of different references to use of race and ethnicity information in order to adjudicate where there are various rare

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The group, you know, had their own concern that we may not have sufficient for some. you know.

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Ethnic groups. reference data in order to call a variant are rare or not.

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We also were interested in, you know, potentially documenting founder effects, or any ethnic specific variants with the imperfect scheme that we came up with, and also because we knew that even though a variant

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that is pathogenic is supposed to be pathogenic across ethnic groups.

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Assuming that the evidence is consistent throughout. there may be some clinical variability in the presentation of someone's condition depending on their ethnic background because they may have a genotype or an environment a

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genotypic, most importantly background that can influence that.

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So we wanted to also document that information. I would say also that this is data that you know it's not perfect.

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There are disadvantages to How this was done, you know, for example, the categories are sociopolitical, not biological.

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You know it could have been, for example, match to instead of using nih looking at nomad, or exact, and saying, You know what are the reference groups, and then you know, matching it as such.

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Also it's self-reported quote unquote data.

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But we also know that It's clinician reported most of the time, and, in fact, we have some preliminary data that we have been working with Alice.

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You know, suggesting that the mismatch between what a patient would self identify as and what a clinician would say.

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That patient is. there are discrepancies you know somewhere around 6, 7%.

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It's preliminary data so don't quote me and that was also based on personal experience.

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I was actually one time I was able to see the Emr

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During one of my primary care visits, and I was on the record described as White European, not Hispanic, and not anything else.

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So it was eventually fixed. but you know nobody ever asked me what was my ancestry, so I think that I hope that answers your question. Yes, thank you so much.

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Anna, and actually similar to your personal testimony. That was something that I wanted to share today as well.

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Just in terms of my lived experience navigating the healthcare system, and I think as a scientist and as someone who is aware of the inequities within the system and the the issues that need to be addressed

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and also based on my personal experience of encountering healthcare providers who did not always listen to me and who may have had their own agenda at times.

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If i'm seeing a new provider I may not always fill in my clinical profile completely, especially if it's someone I may not have to see face to face at times, I may not select black African American because I

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want them to. I want to see if it makes the difference in terms of how someone will treat me at times.

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But I actually had the experience a few months ago, where I went to a new healthcare system.

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I had not completed that information. but then, when I went to grab my file to add more to it,

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That information was self assigned to me, and it just made me reflect on.

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You know, this happens way more common than we realize. And again, these are the data elements that are being sent to the laboratories that are being used and form the guidelines that we are developing.

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That will be implemented in clinic to serve our patients.

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So thank you very much for that. one thing that both of you spoke to in your presentations today. was really this theme of our standards, or the default being status quo. and the fact that the status quo does not

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serve everyone. It has not started everyone to date and we really need to be able to change that.

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So that again, everyone can benefit from the advancements and genomic medicine. And to add onto that, I wanted to hear from both of you as you collected your data.

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Did. Were there ever opportunities to include the patient voice or the community voice, or the population voice, to see if there may be differences again, and how individual self identify to even inform if maybe we we, as scientists as the clinical

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medical community. If we should revisit the categories that we are using, granted they are driven by Ov.

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At times. But if we hear from our patients in our population, is that these are not the population, the the categories that they actually use?

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Should we consider changing that? So it's just wondering If either do you have the opportunity to consider, including that patient perspective, the patient or population voice in your studies

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In my study. No, that did not come up. I do recognize that the patient experience and perspective is fundamental for implementation.

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So an opportunity to go back would also include

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A concurrent effort to collect the patient experience that's an excellent question.

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So if if changes were to be made corporate wide, I think it would be ideal to have a patient advocate voice within, like the committees that make decisions about which categories would be included, or not my my very social

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experimentation and and brief research into this has mostly been asking my friends of color, my friends, in underrepresented populations.

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What do they fill out when they go to the doctor and like how do do they remember what they said in the census and like, Do these categories like actually mean something to you, or or not?

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And even like even between groups, there's like complete different perspective like I have a friend who's also a geneticist also also from my country, and he's like have you told people that like we don't like

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Latinx, and just like because we don't use we don't we?

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When we are in Latin America we don't describe ourselves as Latino or Latina, and and even in the translation in English, why can't it just be Latin? so?

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There's a lot of questions like I have no issues with Latin or Latinx, but, like it is so brought even between, like a group of friends.

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How how they describe. so I can't Imagine that it would be even more complex within within patients and families. Thank you so much.

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Thank you both and Laura. I really appreciated that image that you shared with us.

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In terms of the Omb category classification standards for for race, and I actually took myself through the exercise where I decided to rewind the hands of time and go back 100 years to see what are the options that

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would have been available to me 100 years ago, and I saw that at that time I would have had the option to be probably classified as black negro or mulatto.

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And again, that designation would have been a function of who who was at the house that day, who completed

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The survey for me. but I also went through the practice with hopefully a person that everyone here is familiar with

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I went through the exercise with Henrietta lacked, who was born in 1920, and she died in 1951.

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So in 1920, when Henrietta Lax was born, the options to have selected black negro or mulatto were available, but when she died in 90 51 the only option that was about her since this data was the

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category Negro So I really just wanted to give those examples just to highlight the evolution of the data that we are collecting.

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And again recognizing the power of the power that we are giving these data elements.

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Again in really impacting and influencing patient car ultimately So i'm gonna go to the chat just again to incorporate more more of our audience commentary and questions.

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But I do encourage audience members. Please come off camera or come on to the screen.

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If you have questions, would definitely love for you to turn on your might.

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So that we can hear your questions as well. But I will read a question from Julie.

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Richard and she says you use the term white, while nomad uses European.

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If we are using the patient data to compare it to large data sets, would you recommend harmonization of data sets and explanation of the relevance of the question to patients and ordering physicians?

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, i'll just point out that heidi is on who is the pi of nomad?

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And I think a lot of people misunderstand no mad categories.

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So she may wanna comment, Why, they use European. Okay, thank you for that.

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Shared. and Heidi, please feel free to time in again.

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This. We want this to be an engaging discussion. So not just tasking our presenters to speak today.

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Yeah. So So you know, all of our categories are based on the Pc.

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Analysis. the labels themselves. it's under discussion right now, in fact, the other day the all of Nomad Council was having a discussion about whether to remove all of the labels and use like Tca 3 Pca

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8, which we actually decided was not we're not quite ready for yet, because often one is having to compare this information that's derived genomically to other data that is not drive genomically and trying to match things up becomes

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very difficult. so I guess the the end answer is that we are wanting to engage in a thoughtful dialogue.

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With the community on what are the appropriate terminologies?

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Nomad will always do it based on the genomic data.

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But how we label the the those rubins based on the genomic data we are very open to alluring.

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Can I say something briefly? Yes, please. First of all, that was wonderful. Dr. Ram.

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And out of his. Your questions have been so thoughtful.

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In general. you guys are making me think about so many things.

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But here is exactly the issue that we have right so like if if it's an ma filling out my requisition form, and we have the categories that I showed you guys in my slides.

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So I think we have African, American black. We have hispanic, we have Asian, and we have white, and they just grabbed the information from the medical record, not the genetics.

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Note not the pedigree, and it's a person from the Middle East.

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That's an omb category. white you can't match that to pca component analysis right like It's just It's such a flawed system.

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And even you know, and even if the patient doesn't understand that they are being asked for their ancestors place of you know, you know where they're great great great great grandparents were born even when we ask a question like

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country of origin, which we added to one of our to our requisition forms, and a lot of times it's U.S.A. like not informative. You know It's just and I and I just don't know that a lot of

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people are putting those things together, I know everybody here. is but I think that's just difficult to reconcile that complete difference between the categories that we use in federal forms and for funding, and the categories that we should

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be looking at for things that are genomic and genetic research.

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That is not not a health disparities research, not not research regarding the effects of race and racism, but the effects of something.

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You know, Genomic. Well, the other thing is really in an ideal world.

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All the genetic testing laboratories would include a small number of snips, and these panels have been defined so that every patient they test, whether you're doing a single gene test or a whole genome, or exome would have a you

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know a set of variants, that can inform the background the more data you have the more precise that is, but at least it's genetically, you know, determined, and that's the kind of information we need to inform our genetic

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analysis it's not the information one might prioritize around disparities in access to genetic testing, and things like that which is an entirely separate question that we need to also focus on But it.

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If we're focused, you know, on how do we use this information in clinical genetic testing the closer. it is to the genetic data that the better I agree Heidi. and I would add that to complement the

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you know, biological data from snip markers. We should also be thinking about protocols to teach clinicians how to ask properly this information, and also concurrently educate the community about the importance.

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Of sharing this information. So we have the whole picture, both by biological and sociopolitical.

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Thank you all so much. This has been a tremendous discussion today.

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Thank you, Laura. Thank you, Anna. for really sharing your knowledge and your expertise with us today, and thank you to the audience members.

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For your your phenomenal questions. So again, thank you for everyone who attended today.

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Attendees. I would like to ask and encourage you to return the post.

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Lc. Conversation Survey, which will be posted in the chat.

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And it will Also you will receive it via email shortly after the event as well.

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If you have any questions or any phone up suggestions, we encourage you to email info at Lc.

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Hub, dot org, and Mildred, I will turn it over to you. Thank you.

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Just the last request for everyone to propose new Lc. conversations.

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These are really community driven. the topics are based on what you all want to talk about.

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So please feel free to send in a proposal to us at info dot healthcare.

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Thank you.