00:32:24 Angelica Johnson: Welcome to ELSIconversations! We are glad you will spend the hour with us. We ask that all attendees please abide by the code of conduct, which can be found here: https://elsihub.org/news/code-conduct

00:33:39 Angelica Johnson: Join the ELSI scholar directory: https://elsihub.org/form/submit-scholar

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This Q&A/networking event will last approximately one hour

Use the "Raise Hand" zoom feature to speak or enter your questions/comments in chat. Remember to lower your hand after you’ve been called on

If you require assistance send a direct message to Dounya Alami-Nassif in this meeting or email info@elsihub.org

00:38:55 Alice Popejoy: Respond at PollEv.com/popejoy

00:39:13 Alice Popejoy: OR Text POPEJOY to (747) 444-3548

00:39:29 Alice Popejoy: You can join the session and then reply to each question

00:39:30 Angelica Johnson: https://pollev.com/popejoy

00:46:10 Angelica Johnson: Moderator: Altovise Ewing, PhD, LCGC

Biography: https://thechrysalisinitiative.org/altovise-ewing/

00:49:09 Angelica Johnson: Speaker: Laura Duque Lasio, MD

Biography: https://pathology.utahhealth.acsitefactory.com/pathology/fellows/laura-duque-lasio

00:55:11 Angelica Johnson: Speaker: Ana Morales, MS, LGC

Biography: https://clinicalgenome.org/about/people/staff/morales-1691

01:03:26 Sharon Plon: Anna - can you confirm whether individuals could check more than one category, e.g. can an ordering physician selecte Hispanic and Black/African-American on that list?

01:12:11 Michelle Moore: the point about the limitations on our ability to protest because of our reliance on federal funding is soooo true and so difficult to balance

01:18:35 Cristiane Duarte: If NIH modifies its approach, we may also see real change follow. At least we need to stop imposing US-based categories to studies done outside of the US.

01:21:05 Julie Richer: You used the term White, while gnomAD uses European. If we are using the patient data to compare it to large datasets, would you recommend harmonization of data set and explanation of the relevance of the question to patients and ordering physicians?

01:21:22 Sharon Plon: Altovise's comment if critical. Really important if we are going to make new recommendations that it does include the patient voice.

01:21:34 Linda Merickel: Very important comment - about who actually fills in the boxes on the questionnaire - the clinician, the patient, the nurse, the phlebotomist, the lab personnel - all of this makes a difference.

01:23:03 Mildred Cho: Putting aside for the moment the scientific inaccuracy of the status quo race and ethnicity categories, given that journals are increasingly recommending and requiring authors to report how these data were collected and ascertained, how can researchers who use data from clinical labs find that out? Do labs make that public? Hopefully, researchers will have a way to become aware of changes to laboratory practice.

01:23:05 Kimberly Foss: I think that is another really important point. Patients don’t always know or agree on how to identify

01:27:15 Sharon Plon: But gnomAD is derived from genomic data and requisition forms are self-reported data.

01:30:22 Hila Milo Rasouly: Thank you!

01:30:26 Angelica Johnson: We would appreciate your feedback. Please fill out our survey to discuss your experience and to make suggestions for topics and speakers:

https://cumc.co1.qualtrics.com/jfe/form/SV\_2uhPW8Miyg4P5sy

01:31:16 M. Laura Duque Lasio: Thank you everyone!!! It was a pleasure to be here!

01:31:23 Ana Morales: Thanks everyone!

01:31:25 Sharon Plon: Wonderful session